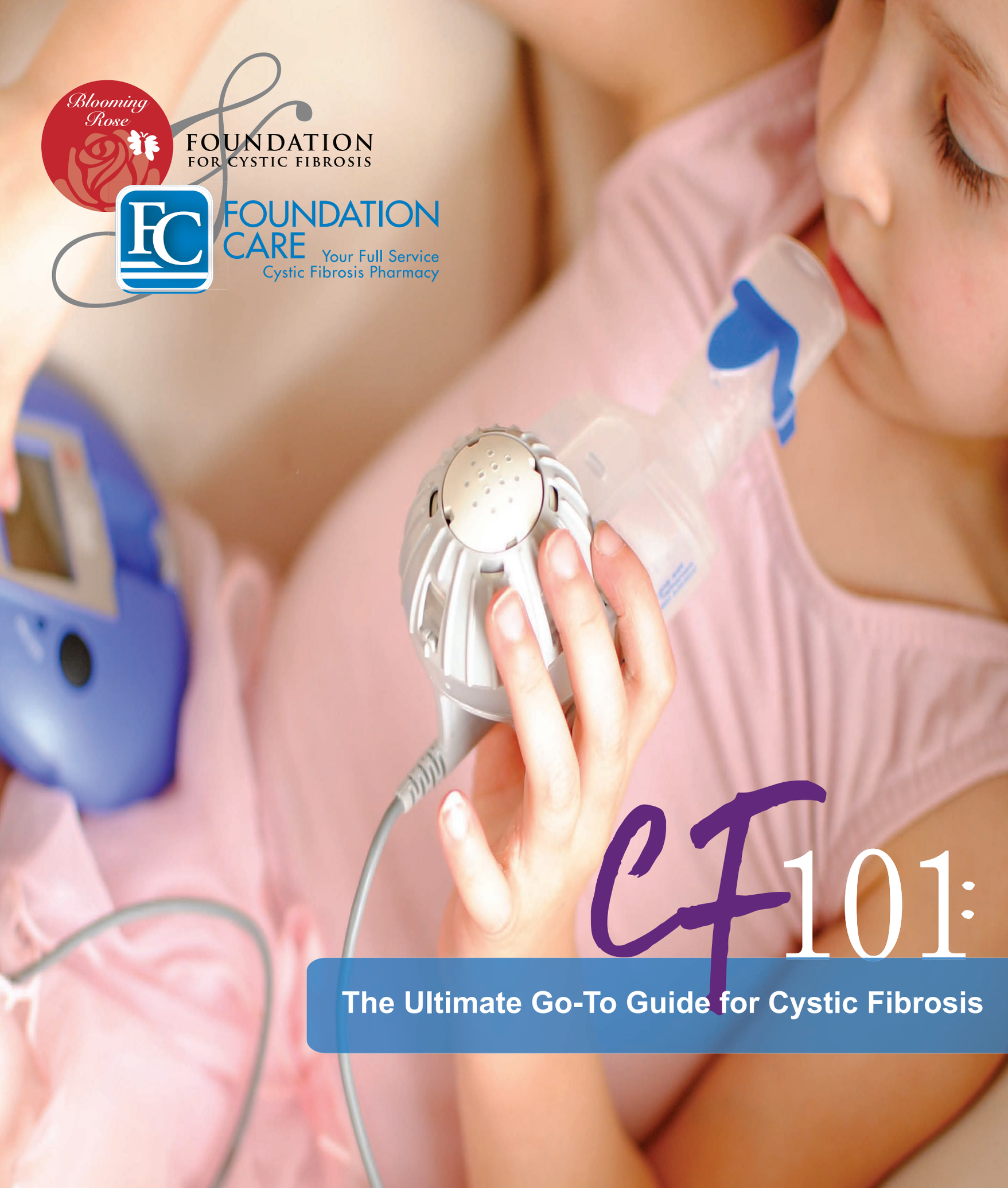
Blooming Rose
FOUNDATION
FOR CYSTIC FIBROSIS
FC
FOUNDATION
CARE
Your Full Service
Cystic Fibrosis Pharmacy
CF 101:
The Ultimate Go-To Guide for Cystic Fibrosis

We would like to thank the following individuals for their professional insight and contribution to this project. Without their help and willingness to read through and review every page, this book would not be the quality reference guide that it is today.

Alec Kirchhoefer, PharmD Candidate
University of Missouri – Kansas City
Foundation Care Pharmacy Intern

Daniel Blakeley, RPh, MBA
Foundation Care Pharmacy
Pharmacist

John Nash, MSW, MLSW
Albany Medical Center Pediatric/Adult Cystic Fibrosis Program
Social Worker

Lise Hippe, PharmD Candidate
Creighton University
Foundation Care Pharmacy Intern

Michael Schultz, RPh
Foundation Care Pharmacy
Pharmacist

Roberta Aregi-Cox, RRT
Children's Hospital Colorado
Cystic Fibrosis Center Respiratory Therapist

Researched, written and designed by:

Courtney Schultz
Foundation Care Pharmacy
Marketing Associate

Heather Glennon
Foundation Care Pharmacy
Marketing Associate

Kathleen Quinn, BSW, CEO
Blooming Rose Foundation
Founder & CEO

This project was funded by:

Foundation Care Pharmacy

BRF: ABOUT

Kathleen Quinn, CEO and Founder
My daughter Maylie was diagnosed with Cystic Fibrosis just before her third birthday in Feb. 2009. I knew very little about CF, except that it is a disease whose name alone seems to send a slight chill through your body. I started Blooming Rose Foundation (BRF) to help give families hope and positive news, information, and advice after diagnosis, including fundraising and access to online resources in the CF community.

Blooming Rose
FOUNDATION
FOR CYSTIC FIBROSIS

ABOUT BRF

The Blooming Rose Foundation was created to give hope to families immediately following CF diagnosis, fundraise to positively reach a vast array of individuals, and offer an online resource for individuals, families, and friends in the CF community. The goal is to help them find up to date research and links to encouraging websites and blogs, as well as connect with other families and adults with CF. Blooming Rose Foundation talks with families about raising a child who is thriving with CF; focusing on the positive outlook and breakthrough treatments available now and on the horizon.

Following a CF diagnosis, BRF offers support services to families, nationwide. Our services include contact with the family, a list of resources and websites as well as brochures and informational packets that are donated from BRF approved CF foundations and organizations. BRF also offers an extensive website with links to parents who have children thriving with CF, adults who are thriving with CF, as well as informative websites that we encourage parents to read through to see the potential of their child. In addition to social services, BRF has a heavy focus on fundraising, both locally as well as nationally, effecting policy change to help our environment to be safer for our children as well as promoting advocacy through proactive parenting.

BRF STAFF & BOARD

Mike Porco
Chief Operating Officer (COO)

Dr. Michael S. Schechter, MD, MPH
Director of the Emory Cystic Fibrosis Clinic
Physician, Professor and Researcher

John Nash, MSW, MLSW
Albany Medical Center
Pediatric/Adult Cystic Fibrosis Program
Social Worker

Dr. Patrick Sosnay, MD
Johns Hopkins School of Medicine
Pulmonary and Critical Care
Physician, Professor and Researcher

Jamie Wood, BSC
Sir Charles Gairdner Hospital, Nedlands,
Western Australia
Senior Physiotherapist,
Cystic Fibrosis/Bronchiectasis

Roberta Aregi-Cox, RRT
Children's Hospital Colorado
Cystic Fibrosis Center Respiratory Therapist

Dr. Catherine McDonald, PhD, RD, CSP
Primary Children's Medical Center
Cystic Fibrosis Dietician

The Blooming Rose Foundation
Bozeman, MT
Ph: 406-599-0139
www.bloomingrosefoundation.com

BRF: ASK THE EXPERTS

FOUNDATION FOR CYSTIC FIBROSIS

www.bloomingrosefoundation.org

ASK THE CYSTIC FIBROSIS EXPERTS

The Blooming Rose Foundation (BRF) offers support, education, and advocacy services to individuals and families living with cystic fibrosis. In an effort to enhance our educational capabilities, BRF has formed a panel of experts to answer questions pertaining to CF.

The BRF panel blends the expertise of medical professionals and the passion and experience of individuals, advocates, and parents living with CF. Our members are widely considered leaders of their fields and have dedicated their entire careers to mitigating the consequences of CF. Through our panel, we strive to be a supportive community dedicated to the provision of insightful information and inspiration. Our goal is to help persons with cystic fibrosis live well.

For information on our "Ask the CF Experts" program visit www.bloomingrosefoundation.org

The answers and advice of "Ask the CF Experts" is for informational purposes only. Content is not intended to be a substitute for professional medical advice, diagnosis, or treatment. Always seek the advice of your physician or other qualified health provider with any questions you may have regarding Cystic Fibrosis. BRF does not recommend or endorse any specific tests, physicians, products, procedures, opinions, or other information that may be mentioned. Reliance on any information provided by BRF, BRF professionals/experts, others appearing on the site at the invitation of BRF, or other visitors is solely at your own risk. The Site may contain health- or medical-related materials that are contrary to your doctors advice, please discuss this thoroughly prior to making any treatment changes.

Post a question concerning cystic fibrosis, and our expert panel will respond with pertinent information, advice, and insight.

CF PANEL EXPERTS

Professional Experts:

Angie Bates, DPT
Meg Benefield, MSW, LICSW
Roberta Aregi-Cox, RRT
Dr. Foster Cline, MD
Dr. Douglas Conrad, MD
Rev. Morrie Adams-Griffin
Kate Gettel, RN, BSN
Lisa C. Greene, BS CCP
Rebecca L. Hefele, R.Ph
Dr. Terri Laguna, MD, MSCS, FCCP, FAAP
Dr. Jerimiah Lysinger, MD
Dr. Michael S. Schechter, MD, MPH
Michael Schultz, R.Ph
Laura Thibedeau Bauer, MS, RD
Andrea Wood, RN, BSN, CCM

Experiential Experts:

Isa Stenzel Byrnes, MSW, MPH
Jerry Cahill
Sharlie Ross Kaltenbach
Aimee Lecointre
Somer Love
Josh Mogren
Emily Schaller
Ronnie Sharpe
Walter Van Praag

BRF PROJECTS & PROGRAMS

Ask the Experts
Cystic fibrosis is a complex genetic disease that manifests itself uniquely and demands a multitude of medications and treatment techniques. Because of this, individuals and parents of children with CF often have questions that are left unanswered by traditional sources. To provide resolutions, The Blooming Rose Foundation has established a national panel of CF experts—pulmonologists, pharmacologists, adults living with CF, respiratory therapists, nutritionists, and mental health experts. Through a direct online forum we connect patients and parents with professionals.

Bubble Pep
Cystic fibrosis is often characterized by the accumulation of mucus in the lungs. In order to mitigate infection and maintain proper lung function, it is critical to loosen and clear the mucus. Rapidly forcing air through the lungs and trachea is an excellent means to achieve this. To encourage children to effectively engage in airway clearance techniques, the Blooming Rose Foundation has devised the Bubble Pep. Children blow through the tube, have fun making bubbles, and simultaneously keeping their lungs strong and healthy.

Marshmallow Gun
Cystic fibrosis is often characterized by the accumulation of mucus in the lungs. In order to mitigate infection and maintain proper lung function, it is critical to loosen and clear the mucus. Rapidly forcing air through the airway is great way to achieve this. To encourage children to frequently engage in airway clearance techniques, The Blooming Rose Foundation provides children with marshmallow guns. A blowgun without the poisonous darts, the marshmallow gun allows children to engage with siblings and friends while simultaneously supporting lung health.

Blooming Rose
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FOR CYSTIC FIBROSIS

www.bloomingrosefoundation.org

Nutritional Advocacy and Education
Individuals with cystic fibrosis often have difficulty digesting food. Subsequently, it is critical for them—especially children—to consume adequate calories to maintain proper bodyweight. Because of this, nutritional guidelines for CF patients endorse high-caloric diets. However, these guidelines neglect to emphasize the importance of micronutrients. New research has indicated that non-cystic fibrosis lungs appear to have more natural antioxidants than cystic fibrosis lungs. The lack of natural antioxidants is linked to the inflammation and infection cycle of CF. People can gain health benefits by increasing their intake of antioxidants through the consumption of fruit and vegetables. The Blooming Rose Foundation is focused on efforts to educate the CF community and restructure the nutritional guidelines to emphasize micronutrient and antioxidant consumption.

Exercise Therapy Advocacy and Education
Cystic fibrosis is often characterized by the accumulation of mucus in the lungs. In order to mitigate infection and maintain proper lung function, it is critical to loosen and clear the mucus. The CF community has embraced many passive airway clearance techniques, but these only provide mediocre results. Instead of passive therapies, The Blooming Rose Foundation has found that an extremely active lifestyle, with ample aerobic exercise, is the most effective way to keep the lungs clear. We strongly promote and advocate for exercise therapy as a means for sustained lung health and prolonged lung transplants.

New Diagnosis Packets
When their child is diagnosed with cystic fibrosis, parents cannot help but feel fear, confusion, pain, and isolation. The Blooming Rose Foundation offers support services to these families. We connect with families and provide pertinent resources, brochures, and informational packets. We listen to their concerns, direct their questions, and link them with other parents of children with CF. Our New Diagnosis Packets provide tools, knowledge, and access to the CF community. They provide hope.

Patient Assistance Programs
Cystic fibrosis is an intense disease that requires rigorous medication regimens, expensive treatment devices, and relatively frequent hospitalizations. Thankfully, there are several nonprofit organizations and philanthropic divisions of pharmaceutical companies that offer support to CF patients and families. The Blooming Rose Foundation supports individuals with CF by connecting them with the organizations that best meet their needs and relieve financial burdens.

FOUNDATION CARE: ABOUT

FOUNDATION CARE

Mike Schultz & **Dan Blakeley**, longtime friends and fellow pharmacists, started Foundation Care (FC) in 2004 to assist with the launch of a highly efficient nebulizer developed for cystic fibrosis (CF) patients. Once the nebulizer became available to the public, the pair decided to expand their business capabilities to meet the broader needs of the CF community.

ABOUT FC

We are Foundation Care, a full service pharmacy serving patients nationwide. We provide retail prescription needs, as well as specialty care to patients challenged by rare, chronic illnesses, such as Bronchiectasis, Cystic Fibrosis, and Diabetes.

Our relationships with caregivers, physicians, and insurance providers across the nation ensure that each patient receives the expertise and guidance needed in today's complex healthcare world. Our personalized service from our professional staff consistently exceeds our patients' expectations. We are dedicated to providing patient focused care, specialized medications, disease management, and the highest standard of customer service.

We do more than fill prescriptions; we work to make your treatment easier and more affordable.

FC STAFF

Pharmacy Staff

Our Pharmacists and Certified Pharmacy Technicians pride themselves on offering comprehensive patient services including dispensing, compounding and counseling. We want to ensure that you are fully supported on your treatment and pharmacy needs. At Foundation Care, we have a pharmacist on call 24/7/365. Our 'round the clock availability means patients will receive prompt and professional attention.

Compounding Technicians

At Foundation Care, we have highly trained and experienced Compounding Technicians dedicated to customizing medications to meet a doctor's orders and each patient's specific needs. Our facility houses state of the art equipment to ensure that the final product prescribed by a physician is prepared to the highest standards.

Patient Care Representatives

Foundation Care's Patient Care Representatives coordinate all aspects of patient care such as working with physicians, providing knowledge on medication and supplies, and organizing delivery of medications. Our Patient Care Representatives provide the personal attention our patients deserve by offering support, guidance and answers to questions.

Reimbursement Specialists

Our dedicated Reimbursement Specialists are knowledgeable and up-to-date on all insurance matters. They know who to call, what questions to ask and how to ensure you're getting the most out of your insurance and associated benefits. Our staff will even assist you in enrolling in patient and copay assistance programs if it will save you money. We guarantee our patients receive the most out of their benefit plans.

Shipping & Logistics Team

Our Shipping and Logistics Team ensures all packages make it to the requested location on time and in perfect condition. No matter the time of day or weather outside, this department knows what steps to take to complete an order as promised with no cost to the patient.

Office Support Team

Our Office Support Team involves everyone from Marketing to Accounting. These individuals ensure all licenses and procedures are up-to-date, our facility is up-to-code and our services can reach patients, physicians and businesses nationwide. They also stay current on all pharmacy trends, providing our online followers with information, and creating new ways of notifying our customers of our entire scope of services.

FOUNDATION CARE PHARMACY

4010 Wedgeway Ct • Earth City, MO 63045 • Ph: (877) 291-1122 • F: (877) 291-1155 • www.FoundCare.com

FOUNDATION CARE: SERVICES

SERVICES AT FOUNDATION CARE

Full Service Retail Pharmacy

There is no prescription too big or too small for Foundation Care. We will be your "one-stop-shop" for healthcare needs.

Specialty Pharmacy Services

Our pharmacists work with physicians to customize treatment plans best suited for each individual patient. In addition to providing prescription and nonprescription medications, Foundation Care Pharmacy is equipped to provide specialty products, devices and compounding services.

Compounding Services

No two Foundation Care patients are alike; that's why we make it our mission to do what we can to meet each individual patient need. To ensure they receive the product they are prescribed in the form they require, Foundation Care will customize each medication based on the needs of each patient (as determined by a physician).
Foundation Care has been accredited by the Pharmacy Compounding Accreditation Board since 2009.

Reimbursement Assistance

Navigating through the ever-changing healthcare world can be overwhelming. At Foundation Care, we have an entire Reimbursement Team that knows who to call, what questions to ask and how to ensure every patient is getting the most out of their insurance and associated benefits.

Compliance & Adherence

We want our patients to receive the best possible results from their treatments, which is why Foundation Care offers personalized refill reminders and reimbursement assistance with each and every order! The key to receiving top results is medication compliance – a topic our pharmacists are passionate about and our entire team is happy to help with.

Easy Refills

Convenience is the key to compliance! Foundation Care is doing its best to make refilling prescriptions as convenient as possible. Patients can now choose how they want to be notified of upcoming refills, including:

- Calls
- Texts
- Emails
- Online MyCARE Account

ACCREDITATIONS

Accreditation Commission for Health Care (ACHC)
Specialty Pharmacy Accreditation

e-Advertiser Approval by The National Association of Boards of Pharmacy (NABP)

Better Business Bureau (BBB)

Healthcare Quality Association on Accreditation (HQAA)
Durable Medical Equipment (DME) Accreditation

Pharmacy Compounding Accreditation Board (PCAB)
Compounding Accreditation

Verified-Accredited Wholesale Distributors (VAWD)
Drug Distribution Accreditation

FC SPECIALS & PROMOTIONS

FREE SHIPPING AND HANDLING ON ALL PRODUCTS

REFER-A-FRIEND PROGRAM

For each of your friends who become a Foundation Care customer, you will receive a $25 VISA gift card. PLUS, your friend who places a first prescription drug order at Foundation Care will also receive a $25 VISA gift card. It's easy! Have your friend fill out a referral card (found online) and submit it with their first prescription to Foundation Care.

*Cayston®

For every fill of your Cayston prescription, Foundation Care will provide you with Hypertonic Saline FREE of charge!

*Colistimethate, Tobramycin &/or TOBI®

For each fill of your Colistimethate, Tobramycin, and/or TOBI prescription, Foundation Care will provide you with ChoiceFul™ Vitamins, a PARI LC PLUS, and Hypertonic Saline FREE of charge!

*Colistimethate &/or Tobramycin

Patients who receive their nebulized chronic inhaled antibiotic from Foundation Care may be eligible for a Trio® Electronic Nebulizer. The Trio is provided to the patient with a "no charge lease" if they participate in our Respiratory Medication Management Program (RMMP). The RMMP is a patient compliance program to help motivate patients to take their medications as prescribed and report compliance information back to the patient's CF coordinator and physician. If a patient becomes non-compliant, the patient is then responsible for the lease payments or can return the Trio nebulizer. Information on enrolling a patient is available by calling toll-free at (877) 291-1122.

*Pancreatic Enzymes

For every fill of your Pancreatic Enzyme prescription, Foundation Care will provide you with Hypertonic Saline OR ChoiceFul™ Vitamins FREE of charge!

*TOBI® Podhaler™

For each fill of your TOBI Podhaler prescription, Foundation Care will provide you with ChoiceFul™ Vitamins and Hypertonic Saline FREE of charge!

*Altera® (Cayston®) &/or Trio®

Patients receiving their Cayston/Altera and/or Trio from Foundation Care will receive our cleaning kit with their first shipment.
Foundation Care developed this nebulizer cleaning kit with the helpful feedback of patients, physicians and our staff. Our pharmacists and patient care representatives have over eight years of experience supporting PARI's eFlow technology. We have established the most effective methods of troubleshooting nebulizers and determined what method of cleaning works best for each patient.

**Offer may not be available in all areas. This offer is good for qualified customers only. This offer is not valid for prescriptions purchased under Medicaid, Medicare or similar federal or state programs or where prohibited by law. Foundation Care reserves the right to amend or discontinue this offer at any time without notice.*

FOUNDATION CARE: CONTACT US

CONTACT

4010 Wedgeway Ct
Earth City, MO 63045

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Phone: (314) 291-1122
Toll-Free Phone: (877) 291-1122

•

Fax: (314) 291-1133
Toll-Free Fax: (877) 291-1155

•

Email: help@foundcare.com

Website: www.FoundCare.com

JOIN OUR SOCIAL CIRCLE!

Facebook
www.facebook.com/FoundationCarePharmacy

Twitter
https://twitter.com/foundationcare

LinkedIn
www.linkedin.com/groups/Foundation-Care-Pharmacy-3087041

Blog
www.foundcare.com/news/blog

Pinterest
http://pinterest.com/foundcare/

YouTube
www.youtube.com/FoundationCare

PATIENT ASSISTANCE

Cystic Fibrosis can be overwhelming at times and the financial burden it places on families creates difficult choices in healthcare. It can limit treatment options or create a lack of adherence to medication therapies.

The Blooming Rose Foundation and Foundation Care are dedicated to providing resources that can help patients and family members afford their medications and devices.

We hope that you find a program that is right for you.

Enclosed is a list of programs and resources that can help you find financial assistance and allow you to learn about the options available in healthcare coverage, including government assistance and patient assistance programs.

Patient Assistance Programs*

The programs are usually sponsored by pharmaceutical companies and provide free or discounted medication to low-to-moderate income, uninsured and underinsured people who meet the guidelines. Eligibility and application requirements vary from program to program.

Patient Assistance Resources

These resources include nonprofit organizations that provide financial assistance or act as a liaison between the patient and the insurer.

Government Programs*

These are state and federal programs to help needy families and individuals with the cost of healthcare. These include Medicare and Medicaid.

**Information on this page was found at www.NeedyMeds.com.*

GOVERNMENT PROGRAMS

List provided by Cystic Fibrosis Research, Inc. (CFRI). www.cfri.org

Medicare

Provides health care coverage for people with long-term disabilities *(and most Americans age 65 and older).*

Phone: 1-800-MEDICARE
Website: www.medicare.gov

Supplemental Security Income (SSI) Program

U.S. Social Security Administration

Website: http://www.ssa.gov/pgm/links_ssi.htm
1-800-772-1213
Deaf or hard of hearing toll-free TTY number: 1-800-325-0778
Social Security Administrative
Office of Public Inquiries
Windsor Park Building
6401 Security Blvd.
Baltimore, MD 21235
You can also contact your local SSI office: https://secure.ssa.gov/apps6z/FOLO/fo001.jsp

ALABAMA

Medicaid: Alabama Medicaid Agency

1-800-362-1504
PO Box 5624
Montgomery, AL 36103-5624
Website: http://www.medicaid.alabama.gov/

ALASKA

Medicaid: Alaska Division of Public Assistance (DPA)

Website: http://dhss.alaska.gov/dpa/Pages/medicaid/default.aspx
1-907-465-3347
PO Box 110640
Juneau, AK 99811-0640
You can also contact your local DPA office: http://dhss.alaska.gov/dpa/Pages/features/org/dpado.aspx

ARIZONA

Medicaid: Arizona Health Care Cost Containment System (AHCCCS)

Website: http://www.azahcccs.gov/
Email: MemberServices@azahcccs.gov
1-800-654-8713
1-602-417-4000
801 East Jefferson Street
Phoenix, AZ 85034
You can also contact your local AHCCCS office: https://www.azdes.gov/faa/contact.asp

UnitedHealthcare Community Plans

Website: http://www.uhccommunityplan.com/plan/state/AZ/index

ARKANSAS

Medicaid: Arkansas Department of Human Services (DHS)

Website: https://www.medicaid.state.ar.us/
1-800-457-4454
1-501-376-2271
Donaghey Plaza South
Slot S201
PO Box 1437
Little Rock, AR 72203
You can also contact your local DHS office:
https://www.medicaid.state.ar.us/InternetSolution/General/units/cooff.aspx

CALIFORNIA

California Children's Services (CCS)
California Department of Health Care Services

Website: http://www.dhcs.ca.gov/services/ccs/Pages/default.aspx
1-916-445-4171
You can also contact your county CCS office:
http://www.dhcs.ca.gov/services/ccs/Pages/CountyOffices.aspx

Genetically Handicapped Persons Program (GHPP)
California Department of Health Care Services

Website: http://www.dhcs.ca.gov/services/ghpp/Pages/default.aspx
1-800-639-0597
1-916-327-0470
GHPP
MS 8100
PO Box 997413
Sacramento, CA 95899-7413

Healthy Families Program (HFP)
California Healthy Families

Website: http://www.healthyfamilies.ca.gov/hfhome.asp
Email: HealthyFamilies@MAXIMUS.com
1-800-880-5305
Healthy Families/Medi-Cal
PO Box 138005
Sacramento, CA 95813
Healthy Families Program (HFP) is California's State Children's Health Insurance Program (SCHIP)

Medi-Cal
California Department of Health Care Services/Department of Social Services

Website: http://www.dhcs.ca.gov/services/medi-cal/Pages/default.aspx
1-916-522-9200
PO Box 997422
MS 4719
Sacramento, CA 95899-7422

Medi-Cal is California's Medicaid program.
You can also contact your county Social Services office: http://www.dhcs.ca.gov/services/medi-cal/Pages/CountyOffices.aspx

COLORADO

Medicaid: Colorado Department of Human Services (CDHS)

Website: http://www.colorado.gov/cs/Satellite/CDHS-Main/CBON/1251575083520
1-303-866-5700
Colorodo Department of Human Services
1575 Sherman Street
Denver, CO 80203
You can also contact your county Department of Human Services:
http://www.colorado.gov/cs/Satellite/CDHS-Main/CBON/1251590215770

CONNECTICUT

Medicaid: Connecticut Department of Social Services (DSS)

Website: http://www.ct.gov/dss/site/default.asp
Email: pgr.dss@ct.gov
1-800-842-1508
Department of Social Service (state of Connecticut)
25 Sigourney Street
Hartford, CT 06106
You can also contact your regional office: http://www.ct.gov/dss/lib/dss/pdfs/medicaid.pdf

ConnTRANS
Connecticut Department of Social Services (DSS)

Website: http://www.ct.gov/dss/cwp/view.asp?a=2353&q=305138
Email: AdultSupportTeam.DSS@ct.gov
1-860-424-5250
Adult Support Unit: Department of Social Services: State of Connecticut
25 Sigourney Street
Hartford, CT 06106
This is Connecticut's program for organ transplant recipients.
Pamphlet discussing organ transplant options: http://www.ct.gov/dss/lib/dss/pdfs/conntrans.pdf

State Supplement Program
Connecticut Department of Social Services (DSS)

Website: http://www.ct.gov/dss/cwp/view.asp?a=2353&q=305138
Email: AdultSupportTeam.DSS@ct.gov
1-860-424-5250
Adult Support Unit: Department of Social Services
25 Sigourney Street
Hartford, CT 06106
You can also contact your regional DSS office: http://www.ct.gov/dss/lib/dss/pdfs/state_supplement_96-4__03.07.pdf

State-Administered General Assistance (SAGA)

Connecticut Department of Social Services (DSS)

Website: http://www.ct.gov/dss/cwp/view.asp?a=2353&q=305152#SAGA
Email: AdultSupportTeam.DSS@ct.gov
1-800-842-1508
25 Sigourney Street
Hartford, CT 06106

Connecticut Pharmaceutical Assistance Contract to the Elderly and Disabled (ConnPACE)
Connecticut Department of Social Services (DSS)

Website: http://www.connpace.com/
1-800-423-5026
ConnPACE
P.O Box 5011
Hartford, CT 06102-5011
Application Website: http://www.connpace.com/index.html

DELAWARE

Children's Community Alternative Disability Program
Delaware Health and Social Services (Division of Medicaid and Medical Assistance)

Website: http://www.dhss.delaware.gov/dhss/dmma/disabledchildren.html
1-800-372-2022
Contact Information for people/agencies within Delaware:
http://www.dhss.delaware.gov/dhss/main/contacts.htm
Delaware Health and Human Services Offices:
http://www.dhss.delaware.gov/dhss/main/maps/dhssmap.htm

Delaware Healthy Children Program
Delaware Health and Social Services (Division of Social Services)

Website: http://www.dhss.delaware.gov/dss/dhcp.html
Delaware Healthy Children Program
PO Box 950
New Castle, DE 19720-9914
1-800-996-9969

Delaware Prescription Assistance Program
Delaware Health and Social Services (Division of Social Services)

Website: http://dhss.delaware.gov/dhss/dmma/dpap.html
You can also contact your County DSS office: http://www.dhss.delaware.gov/dss/contact.html
1-800-996-9969 (Option 2, then Option 1)

Medicaid
Delaware Health and Social Services (Division of Medicaid and Medical Assistance)

Website: http://www.dhss.delaware.gov/dhss/dmma/
You can also apply online: https://assist.dhss.delaware.gov/
1-800-996-9969
Lewis Building
Herman Holloway Sr. Campus

1901 North DuPont Highway
New Castle, DE 19720

FLORIDA

Medicaid
Florida Department of Children and Families

Website: http://www.dcf.state.fl.us/programs/access/medicaid.shtml
You can also apply online: http://www.myflorida.com/accessflorida/
Agency for Health Care Administration
2727 Mahan Drive
Tallahassee, FL 32308
1- (888) 419-3456
Contact information for services provided by Medicaid: http://www.fdhc.state.fl.us/contact/index.shtml\

GEORGIA

Medicaid Georgia Department of Human Resources (DHR) Division of Family and Children Services (DFCS)

Website: http://dch.georgia.gov/00/channel_title/0,2094,31446711_31944826,00.html
(404) 656-4507
Main Office
2 Peachtree Street,
NW Suite 18-486
Atlanta, Georgia 30303
Office of Rural Health Services
502 Seventh Street
South Cordele, GA 31015-1444
You can contact your local DFCS office: http://dfcs.dhs.georgia.gov/complete-list-all-county-offices

HAWAII

Medicaid
Hawaii Med-QUEST

Website: http://hawaii.gov/dhs/health/medquest/
Deparment of Human Services
1390 Miller Street, Room 209
Honolulu, HI 96813
1-808-586-4997
Email: dhs@dhs.hawaii.gov
Contact Information Website:
http://archive.jan2013.hawaii.gov/dhs/main/contact_dept/important_phone_numbers

IDAHO

Medicaid
Idaho Department of Health and Welfare (DHW)

Website: http://www.healthandwelfare.idaho.gov/Medical/Medicaid/tabid/123/Default.aspx
You can contact your local DHW office:
http://www.healthandwelfare.idaho.gov/ContactUs/tabid/127/Default.aspx

ILLINOIS

Circuit Breaker

Illinois Department on Aging

Website: http://www.cbrx.il.gov/
Email: ilsenior@aging.state.il.us
Other contact Information: http://www.cbrx.il.gov/aging/1aboutidoa/contact_idoa.htm
1-800-624-2459
1-800-252-8966
Deaf or hard of hearing toll-free TTY number: 1-888-206-1327
PO Box 19003
Springfield, IL 62794-9003

Illinois Cares Rx

Illinois Department on Aging

Website: http://www.illinoiscaresrx.com/
Email: hfswebmaster@illinois.gov
1-800-252-8966
1-800-226-0768
Deaf or hard of hearing toll-free TTY number: 1-866-675-8440
Illinois Department on Aging
PO Box 19022
Springfield, IL 62794-9022

Medicaid

Illinois Department of Healthcare and Family Services (HFS)

Website: http://www.hfs.illinois.gov/medical/apply.html
Springfield Office
100 South Grand Avenue East
Springfield, Illinois 62762
1-800-843-6154
(217) 557-2134 TTY
Chicago Office
401 South Clinton Street
Chicago, Illinois 60607
1-800-843-6154
(312) 793-2354 TTY
You can contact your local HFS office: http://www.dhs.state.il.us/page.aspx?module=12

INDIANA

Hoosier Healthwise

Indiana Family and Social Services Administration (FSSA)

Website: http://www.in.gov/fssa/ompp/2544.htm
Families can also apply at a conveniently located enrollment center:
http://www.in.gov/fssa/ompp/3030.htm
1-800-457-8283 (agency information)

Hoosier Rx

Indiana Family and Social Services Administration (FSSA)

Website: http://www.in.gov/fssa/ompp/2669.htm
1-317-234-1381
1-866-267-4679
HoosierRx
PO Box 6224
Indianapolis, IN 46206-6224

IOWA

Medicaid

Iowa Department of Human Services (DHS)

Website: http://www.dhs.state.ia.us/Consumers/Health/Medical_Insurance/WhatsAvailable.html
1-800-972-2017
1-515-281-6899
Email: contactdhs@dhs.state.ia.us
You can contact your local DHS office:
http://www.dhs.state.ia.us/Consumers/Find_Help/MapLocations.html

KANSAS

Medicaid & HealthWave

Kansas Health Policy Authority (KHPA)

Website: http://www.kdheks.gov/hcf/healthwave/default.htm
Kansas Health Policy Authority
900 North, Landon State Office Building; 900 Sw Jackson Street
Topeka, KS 66612
1785-296-3981

KENTUCKY

Medicaid

Kentucky Cabinet for Health and Family Services (CHFS)

Website: http://chfs.ky.gov/dms/
1-800-635-2570
Office of the Secretary
275 East Main Street
Frankfort, KY 40621

LOUISIANA

Medicaid

Louisiana Medicaid

Website: http://new.dhh.louisiana.gov/index.cfm/subhome/1/n/331
You can also apply online: https://bhsfweb.dhh.louisiana.gov/OnlineServices/
1-888-342-6207
Louisiana Deapartment of Health and Hospitals
Physical Address:
628 North 4th Street
Batton Rouge, LA 70802
Mailing Address:

Louisiana Department of Health and Hospitals
PO Box 91278
Baton Rouge, LA 70821

MAINE

MaineCare
Maine Department of Health and Human Services (DHHS)

Website: http://www.maine.gov/dhhs/index.shtml
1-800-606-0215
1-207-287-3707
DHHS
221 State Street
Augusta, ME 04333
MaineCare is Maine's Medicaid program.
You can contact your local office: http://www.maine.gov/dhhs/DHSaddresses.htm

Maine Low Cost Drug Program for the Elderly and Disabled and Maine Rx Plus
Maine Department of Human Services

Website: http://www.mejp.org/drugprograms.htm
1-207-626-7058
1-866-626-7059 (toll Free)
Maine Equal Justice
126 Sewall Street
Augusta, ME 04330

MARYLAND

Medicaid
Maryland Department of Human Resources (DHR)

You must contact your Local Department of Social Services (LDSS):
http://www.dhr.state.md.us/county.php
Email: dhrhelp@dhr.state.md.us
1-800-332-6347
311 West Saratoga Street
Baltimore, MD 21201

Maryland Senior Prescription Drug Assistance Program (SPDAP)
Maryland Health Insurance Plan (MHIP)

Website: http://www.marylandspdap.com/
1-800-551-5995
Maryland-SPDAP
c/o Pool Administrators
628 Hebron Ave Suite 212
Glastonbury CT 06033
Deaf or hard of hearing toll-free TTY number: 1-800-877-5156

MASSACHUSETTS

Health Connector (Commonwealth Care)

MassHealth

Website: https://www.mahealthconnector.org/portal/site/connector
Email: membersupport@mahealth.net
1-800-841-2900
1-617-573-1770
1-877-623-6765
One Ashburton Place
11th Floor
Boston, MA 02108
Commonwealth Care Health Insurance Program (Commonwealth Care) is Massachusetts's Medicaid program.

Prescription Advantage
Massachusetts Commonwealth of Massachusetts Executive Office of Elder Affairs

Website: http://www.mass.gov/elders/healthcare/prescription-advantage/
1-800-243-4636
1-617-727-7750
Deaf or hard of hearing toll-free TTY number: 1-800-872-0166
One Ashburton Place
Fifth Floor
Boston, MA 02108

MICHIGAN

Medicaid
Michigan Department of Community Health (MDCH)

Website: http://www.michigan.gov/mdch/0,4612,7-132-2943_4860---,00.html
Email: blakeneys@michigan.gov
1-517-373-3740
Capitol View Building
201 Townsend Street
Lansing, MI 48913

MINNESOTA

Medicaid
Minnesota Department of Human Services (DHS)

Website: www.mn.gov/dhs
1-800-657-3739
1-651-431-2670

MISSISSIPPI

Medicaid
Mississippi Division of Medicaid

Website: http://www.medicaid.ms.gov/
You can also contact your local office: http://www.medicaid.ms.gov/RegionalOffices.aspx
1-800-421-2408
1-601-359-6050
Sillers Building

550 High Street
Suite 1000
Jackson, MS 39201-1399

MISSOURI

MO Healthnet
Missouri Department of Social Services (DSS) / Missouri HealthNet Division

Website: http://www.dss.mo.gov/fsd/msmed.htm
Email: Ask.MHD@dss.mo.gov
1-573-751-3425
MO HealthNet Division
615 Howerton Court
PO Box 6500
Jefferson City, MO 65102
MO Healthnet is Missouri's Medicaid program.
Local Office Website information: http://www.dss.mo.gov/offices.htm

Missouri Rx Plan (MoRx)
Missouri Department of Social Services MO HealthNet Division

Website: http://www.morx.mo.gov/
Email: clinical.services@dss.mo.gov
1-800-375-1406
Missouri Rx Plan
PO Box 6500
205 Jefferson Street
14th Floor
Jefferson City, MO 65102-6500

MONTANA

Medicaid
Montana Department of Public Health and Human Services (DPHHS)

Website: http://www.dphhs.mt.gov/programsservices/medicaid.shtml
You can visit your local Office of Public Assistance (OPA):
http://www.dphhs.mt.gov/contactus/humancommunityservices.shtml
1-800-332-2272

NEBRASKA

Nebraska Medical Assistance Program
Nebraska Department of Health and Human Services

Website: http://dhhs.ne.gov/medicaid/Pages/med_medindex.aspx
1-800-642-6092
301 Centennial Mall South
PO Box 95026
Lincoln, NE 68509-5026
Nebraska Medical Assistance Program is Nebraska's Medicaid program.

NEVADA

Medicaid

Nevada Division of Health Care Financing and Policy

Website: http://dhcfp.nv.gov/Sitemap.htm#Medicaid
Email: techhelp@dhcfp.nv.gov
1-775-684-3676
Nevada Medicaid Central Office
1100 East William Street
Suite 101
Carson City, NV 89701

Nevada Disability Rx

Nevada Department of Health and Human Services

Website: http://dhhs.nv.gov/DisabilityRx.htm
Email: lolson@dhhs.nv.gov
1-866-303-6323
1-775-687-7555
Nevada Disability Rx
Department of Health and Human Services
3416 Goni Road, Suite B-113,
Carson City, NV 89706

NEW HAMPSHIRE

Medicaid

New Hampshire Department of Health and Human Services
Division of Family Assistance

Website: http://www.dhhs.nh.gov/index.htm
1-800-852-3345 (Ext. 4344)
1-603-271-5254
Street Address:
129 Pleasant Street
Concord, NH 03301
Mailing Address:
Office of Medicaid Business & Policy
NH Department of Health & Human Services
129 Pleasant Street
Concord, NH 03301

NEW JERSEY

Medicaid

New Jersey Department of Human Services (DHS)

Website: http://www.state.nj.us/humanservices/dmahs/clients/medicaid/
You can also apply online: http://www.njhelps.org/
1-800-356-1561
Division of Medical Assistance and Health Services
Quakerbridge Plaza
PO Box 712
Trenton, NJ 08625-0712

Pharmaceutical Assistance to the Aged and Disabled program (PAAD)
New Jersey's Department of Health & Senior Services

Website: http://www.state.nj.us/health/seniorbenefits/paad.shtml
1-800-792-9745
PO Box 715
Trenton, NJ 08625-0715

NEW MEXICO

Medicaid
Medical Assistance Division (MAD)

Website: http://www.hsd.state.nm.us/mad/
1-888-997-2583(Toll Free)
(505) 827-3100 (local Santa Fe)
New Mexico Human Services Department's Medical Health Division
PO Box 2348
Santa Fe, NM 87504
Email: MADInfo.HSD@state.nm.us

NEW YORK

Medicaid
New York Department of Health / Human Resources Administration (HRA)

Website: http://www.health.state.ny.us/health_care/medicaid/
Contact Information Website (for more number for specific Medicaid programs)
http://www.health.state.ny.us/health_care/medicaid/program/contact.htm
New York State Department of Health
Corning Tower
Empire State Plaza
Albany, NY 12237

NORTH CAROLINA

Medicaid
North Carolina Department of Health and Human Services (DHHS)

Website: http://www.ncdhhs.gov/dma/medicaid/
You can also apply at your county Department of Social Services (DSS):
http://www.ncdhhs.gov/dss/local/index.htm
1-800-662-7030 (English and Spanish)
1-919-855-4400 (wake forest)
919-733-4851 (TTY for hearing impaired)

NORTH DAKOTA

Medicaid
North Dakota Department of Human Services (NDDHS)

Website: http://www.nd.gov/dhs/services/medicalserv/medicaid/
You may contact your local NDDHS Center: http://www.nd.gov/dhs/locations/regionalhsc/
1-800-472-2622 (Toll Free)
701-328-3480 (TTY for hearing impaired)

OHIO

Medicaid

Ohio Department of Jobs and Family Services (ODJFS)

Website: http://jfs.ohio.gov/OHP/

You can also contact your local office: http://jfs.ohio.gov/County/County_Directory.pdf

Mailing Address:

The Ohio Department of Job and Family Services
30 E. Broad Street, 32nd Floor
Columbus, Ohio 43215

General Phone Numbers:

1-877-852-0010
1-614-466-2100

OKLAHOMA

SoonerCare

Oklahoma Department of Human Services (OKDHS)

Website:
http://www.okdhs.org/programsandservices/health/med/?&MSHiC=65001&L=10&W=MEDICAIDL%

You may contact your local OKDHS Human Services Center: http://www.okdhs.org/okdhslocal/

Email: inforeferral@OKDHS.org

1-405-521-3646

Oklahoma Department of Human Services
Sequoyah Memorial Office Building
2400 N. Lincoln Blvd.
Oklahoma City, OK 73105

SoonerCare is Oklahoma's Medicaid program.

OREGON

Oregon Health Plan (OHP)

Oregon Division of Medical Assistance Programs (DMAP)

Website: http://egov.oregon.gov/DHS/healthplan/

Email: dmap.info@state.or.us

1-800-359-9517

Administrative Office
500 Summer Street, NE
Salem, OR 97301

Oregon Health Plan (OHP) is Oregon's Medicaid program.

Resource List

Oregon Health Connect

Website: http://www.oregonhealthconnect.org/index.cfm?fuseaction=main.prov_list

Email: health.connect@state.or.us

1-855-999-3210

PENNSYLVANIA

Medicaid

Pennsylvania Department of Public Welfare's (DPW) Office of Medical Assistance Programs
1-800-692-7462
Website: http://www.dpw.state.pa.us/

Prescription Assistance (PACEplus)
Pennsylvania Department of Aging
Website: http://www.aging.state.pa.us/portal/server.pt/community/prescription_assistance/17942
1-800-225-7223
1-717-651-3600
Information about local office for PACEplus:
http://www.aging.state.pa.us/portal/server.pt/community/your_local_resources/17952
PO Box 8806
Harrisburg, PA 17105-8806

RHODE ISLAND

Medicaid
Rhode Island Department of Human Services
Website: http://www.dhs.ri.gov/Adults/HealthMedicalServices/tabid/807/Default.aspx
You can contact DHS offices by location:
http://www.dhs.ri.gov/ContactUs/DHSOffices/DHSOfficesbyLocation/tabid/798/Default.aspx
1-401-462-5300

Rhode Island Pharmaceutical Assistance to the Elderly (RIPAE)
Rhode Island Department of Elderly Affairs
Website: http://www.dea.ri.gov/programs/prescription_assist.php
Email: larry@dea.state.ri.us
1-401-462-3000
1-401-462-0474 (TTY)

SOUTH CAROLINA

Medicaid
South Carolina Department of Health and Human Services (DHHS)
Website: https://www.scdhhs.gov/how-to-apply
Email: info@scdhhs.gov
1-888-549-0820
Department of Health and Human Services
PO Box 8206
Columbia, SC 29202-8206
DHHS Local Office: https://www.scdhhs.gov/site-page/dhhs-county-offices

SOUTH DAKOTA

Medicaid
South Dakota Department of Social Services (DSS) Division of Medical Assistance
Website: http://dss.sd.gov/medicaleligibility/
You may apply for Medicaid at your local DSS office: http://dss.sd.gov/offices/index.asp
Email: MedElig@state.sd.us
1-605-773-3165

700 Governors Drive
Pierre, SD 57501

TENNESSEE

TennCare
Bureau of TennCare

Website: http://www.state.tn.us/tenncare/
Additional information: http://www.state.tn.us/tenncare/quick-contactus.html
1-800-342-3145
TennCare
310 Great Circle Road
Nashville, TN 37247

TEXAS

Medicaid
Texas Health and Human Services Commission (HHSC)

Website: http://www.hhsc.state.tx.us/medicaid/med_info.html
Additional information: http://www.hhsc.state.tx.us/about_hhsc/contact/contact.shtml
Email: contact@hhsc.state.tx.us
(800) 252-8263
Brown-Heatly Building
4900 North Lamar Blvd.
Austin, TX 78751-2316

UTAH

Medicaid
Utah Medicaid Program

Website: http://health.utah.gov/medicaid/
Enter your zip code to find your local office: http://jobs.utah.gov/Regions/ec.html
1-800-662-9651
Mailing:
Utah Department of Health
P.O. Box 141010
Salt Lake City, UT 84114-1010
Phone: 801-538-6101
Main Building:
Cannon Health Building
288 North 1460 West
Salt Lake City, UT 84116

VERMONT

Medicaid
Vermont Health Access Plan (VHAP)

Website: http://www.greenmountaincare.org/vermont-health-insurance-plans/vermont-health-access-plan

Green Mountain Care
Office of Vermont Health Access (OVHA)

Website: http://ovha.vermont.gov/
Email: lori.collins@ahs.state.vt.us
Additional Contact Information: http://www.greenmountaincare.org/contact.html

VIRGINIA

Medicaid
Virginia Department of Medical Assistance (DMAS)

Website: http://www.dmas.virginia.gov/
You can contact your local Virginia Department of Social Services (VDSS) office:
http://www.dss.virginia.gov/localagency/
Additional Contact Information: http://dmasva.dmas.virginia.gov/Content_atchs/atchs/ContactUs.pdf
You can contact your local DSHS Division of Developmental Disabilities office:
http://www.dshs.wa.gov/ddd/contacts.shtml
Email: DMAS-info@dmas.virginia.gov
1-800-552-8627 (in state)
1-804-786-6273 (out of state)

WASHINGTON

State Insurance
Washington State Health Insurance Pool (WSHIP)

Website: https://www.wship.org
1-800-877-5187
Additional Contact Information: https://www.wship.org/contact_us.asp

WEST VIRGINIA

Medicaid
West Virginia Department of Social and Health Services (DSHS)

You can contact your local BCF office: http://www.wvdhhr.org/bcf/county/default.asp
You can also apply online: https://www.wvinroads.org/inroads/PGM/ASP/SC001.asp
1-800-562-3022

Medicaid
West Virginia Department of Health and Human Resources (DHHR)
Bureau for Children and Families (BCF)

Website: http://www.wvdhhr.org/bcf/family_assistance/medicaid.asp
1-800-642-8589

WISCONSIN

Medicaid
Wisconsin Department of Health and Family Services (DHFS)

http://dhs.wisconsin.gov/medicaid/
You can apply online: https://access.wisconsin.gov/access/
DHSwebmaster@wisconsin.gov
Department of Health Services
1 West Wilson Street
Madison, WI 53703
General Phone Number: 608-266-1865,

TTY Phone Number: 888-701-1251.

Adult Cystic Fibrosis Program Wisconsin Department of Health and Family Services (DHFS)

Website: https://www.forwardhealth.wi.gov/WIPortal/Tab/42/icscontent/Provider/wcdp/index.htm.spage

Health Insurance Risk-Sharing Plan (HIRSP)
Wisconsin Department of Health and Family Services (DHFS)

http://www.hirsp.org/
HIRSPweb@wpsic.com
1-800-828-4777
1-608-221-4551
1751 W. Broadway
PO Box 8961
Madison, WI 53708-8961

WYOMING

EqualityCare
Department of Family Services (DFS)

Website: http://www.health.wyo.gov/healthcarefin/equalitycare/index.html
1-307-777-5846
Hathaway Building
3rd Floor
2300 Capitol Avenue
Cheyenne, WY 82002
EqualityCare is Wyoming's Medicaid program.
Additional Information: http://www.health.wyo.gov/main/about.html

Wyoming Prescription Drug Assistance Program (PDAP)
Wyoming Department of Health/Office of Healthcare Financing/Office of Pharmacy Services

Website: http://www.health.wyo.gov/healthcarefin/pharmacy/PrescriptionDrugAssistanceProgram.html
Email: pharmacy@health.wyo.gov
1-307-777-7531
6101 Yellowstone Road
Suite 259A
Cheyenne, WY 82002

DISTRICT OF COLUMBIA

Medicaid
District of Columbia Department of Human Services

Website: http://dhcf.dc.gov/service/medicaid
1-202-671-4200
TTY 1-202-671-4495

U.S. VIRGIN ISLANDS

Public Assistance Programs
U.S. Virgin Islands Department of Human Services

Website: http://www.dhs.gov.vi/financial_programs/public_assistance.html

PATIENT ASSISTANCE RESOURCES

PROGRAM: Boomer Esiason Foundation

DESCRIPTION: A dynamic partnership of leaders in the medical and business communities joining with a committed core of volunteers to heighten awareness, education and the quality of life for those affected by cystic fibrosis, while providing financial support to research aimed at finding a cure.
WEBSITE: www.esiason.org/
PHONE: 646-292-7930

PROGRAM: Cystic Fibrosis Patient Assistance Foundation

DESCRIPTION: The Cystic Fibrosis Patient Assistance Foundation (CFPAF) is a non-profit organization that helps patients and their family members living with cystic fibrosis afford the medications and devices they need to manage their disease.
WEBSITE: www.cfpaf.org
PHONE: 1-888-315-4154

PROGRAM: First Hand Foundation

DESCRIPTION: A not-for-profit, 501(c)(3) organization that provides funding for individual children with health-related needs when insurance and other financial resources have been exhausted.
WEBSITE: https://applications.cerner.com/firsthand/default.aspx
PHONE: 816-201-1569

PROGRAM: The Living Breath Foundation Financial Aid

DESCRIPTION: A non-profit organization created to help those living with Cystic Fibrosis. They assist individuals and families with the added expenses associated with having Cystic Fibrosis, which include the extensive costs of prescription medication and medical equipment. In certain situations they provide financial assistance to individuals who have prolonged or frequent absences from work.
WEBSITE: http://www.thelivingbreathfoundation.com/index.html
PHONE: 831-392-5283

PROGRAM: NeedyMeds

DESCRIPTION: NeedyMeds is an online information resource of programs that provide assistance to people who are unable to afford their medications and health care costs. The site maintains current information about many sources of assistance that anyone can use without registering or entering any personal data.
WEBSITE: www.needymeds.org/
PHONE: 978-865-4115

PATIENT ASSISTANCE RESOURCES

PROGRAM: Partnership for Prescription Assistance

DESCRIPTION: Helps qualifying patients without prescription drug coverage get the medicines they need for free or nearly free.
WEBSITE: http://www.pparx.org/en
PHONE: 1-888-4PPA-NOW (1-888-477-2669)

PROGRAM: Patient Advocate Foundation

DESCRIPTION: A national non-profit organization that serves as an active liaison between the patient and their insurer, employer and/or creditors to resolve insurance, job retention and/or debt crisis matters relative to their diagnosis through case managers, doctors and attorneys.
WEBSITE: http://www.patientadvocate.org/
PHONE: 1-800-532-5274

PROGRAM: Patient Access Network Foundation

DESCRIPTION: An independent non-profit organization that provides underinsured patients with co-payment assistance through more than 40 disease-specific funds that give them access to the treatments they need.
WEBSITE: www.panfoundation.org/
PHONE: 1-866-316-7263

PROGRAM: Patient Services, Inc.

DESCRIPTION: A non-profit, charitable organization that recognized the importance of providing a "safety net" for patients with chronic illnesses who were struggling to keep up with expensive premiums and co-payments. Since 1989, they have provided much needed patient assistance and solicited donations to fund thousands of patients and their families in a myriad of disease areas.
WEBSITE: www.patientservicesinc.org/
PHONE: 1-800-366-7741

PROGRAM: RXAssist: Patient Assistance Program Center

DESCRIPTION: Offers a comprehensive database of patient assistance programs, as well as practical tools, news, and articles so that health care professionals and patients can find the information they need, all in one place.
WEBSITE: www.rxassist.org
PHONE: N/A
EMAIL: info@rxassist.org

PATIENT ASSISTANCE PROGRAMS

ABBVIE LABORATORIES

PROGRAM: CFCareFoward Patient Support Program

DESCRIPTION: Provides nutritional support at no charge for people with cystic fibrosis (CF), with multivitamins in softgel, chewable, and liquid formulations, plus a variety of nutritional drinks and bars *(some restrictions apply)*. The CREON Co-pay Program can save you up to $50 per month on your CREON prescriptions. Created to honor young adults with CF as they pursue goals of higher education, the CFCareForward Scholarship has awarded scholarships totaling more than $2 million to bright, young students.
WEBSITE: http://www.creon.com/CFPatients/CFCareForward
PHONE: 1-855-CARE4WD (1-855-227-3493)

PROGRAM: AbbVie Patient Assistance Foundation

DESCRIPTION: Provides AbbVie medicines at no cost to qualified patients who are experiencing financial difficulties and who generally do not have coverage available for these products through private insurance or government funded programs.
WEBSITE: http://www.abbviepaf.org/
PHONE: 1-800-222-6885

APTALIS

PROGRAM: Aptalis Patient Assistance Program

DESCRIPTION: Created to help eligible patients receive financial assistance for certain Aptalis medications.
WEBSITE: www.aptalispap.com
PHONE: 1- 866-514-2442

PROGRAM: Live2Thrive

DESCRIPTION: Created for patients with exocrine pancreatic insufficiency (EPI) due to cystic fibrosis (CF). Eligible patients receive savings on prescription, vitamin, and nutritional supplement costs
WEBSITE: http://www.live2thrive.org/
PHONE: 1-888-936-7371

PROGRAM: Ultresa Patient Support Program

DESCRIPTION: Created for patients with exocrine pancreatic insufficiency (EPI) due to other conditions. Eligible patients receive helpful copay savings on prescription and vitamin costs.
WEBSITE: www.ultresasupport.com/
PHONE: 1-877-275-1925

DIGESTIVE CARE, INC.

PROGRAM: Pertzye® Co-Pay Assistance Program

DESCRIPTION: A cardless program that is fulfilled through the Customer Support Department of the CF Services Pharmacy. The maximum out-of-pocket co-pay expense is only $10.00 (for each 30 day prescription fulfillment) for eligible patients whose insurance covers Pertzye®.
**Program valid until December 31, 2013.*
WEBSITE: http://www.digestivecare.com/patientprograms.shtm
PHONE: 1-877-882-5950

PROGRAM: FIRST START Program

DESCRIPTION: Digestive Care, Inc. provides all institutions with the ability to offer an initial supply of PERTZYE® (pancrelipase) Delayed-Release Capsules "Free of Charge" to your patients.
WEBSITE: http://www.digestivecare.com/patientprograms.shtm
PHONE: 1-877-882-5950

PROGRAM: Assistance Program

DESCRIPTION: Available for patients with financial difficulties. Physicians apply for this program on behalf of their patients. Eligibility is determined on a case-by-case basis through a formal review process at Digestive Care, Inc. Upon approval, a FREE three month supply of Pertzye® will be sent to the requesting physician for distribution to their patient. If another supply is needed, the physician is to submit another enrollment form.
WEBSITE: http://www.digestivecare.com/patientprograms.shtm
PHONE: 1-877-882-5950

PROGRAM: Nutritional Rebate Program

DESCRIPTION: For every 30 day prescription of Pertzye® that is filled, a patient is eligible to receive a maximum rebate of $25.00 from their purchase of vitamin supplements, high calorie drinks or other nutritional food sources. The rebate covers up to a total of $75.00 for each 90-day supply of Pertzye®.
WEBSITE: http://www.digestivecare.com/patientprograms.shtm
PHONE: 1-877-882-5950

ELI LILLY AND COMPANY

PROGRAM: Lilly Cares

DESCRIPTION: Free Lilly medicines for uninsured patients through their doctor's office.
WEBSITE: http://lillytruassist.com/Pages/AboutLillyCares.aspx
PHONE: 1-800-545-6962

PROGRAM: LillyMedicareAnswers
DESCRIPTION: Free Lilly medicines for eligible Medicare patients outside of Medicare Part D prescription plan.
WEBSITE: http://lillytruassist.com/pages/AboutLMCA.aspx
PHONE: 1-877-RXLilly (1-877-795-4559)

PROGRAM: Lilly Camp Care Package Initiative
DESCRIPTION: Insulin medicines and educational resources for eligible Diabetes Camps.
WEBSITE: http://lillytruassist.com/pages/AboutLillyCamp.aspx
PHONE: 1-317-328-7089

GENENTECH

PROGRAM: Genentech® Access to Care Foundation (GATCF)
DESCRIPTION: Created to help patients who are uninsured—or who have been denied coverage for Pulmozyme® (dornase alfa) Inhalation Solution by their health plans. GATCF might be able to help those patients receive Pulmozyme treatment if they meet specific financial and medical criteria.
WEBSITE: http://www.genentech-access.com/pulmozyme/hcp/find-patient-assistance/help-for-uninsured-patients
PHONE: (800) 690-3023

PROGRAM: Pulmozyme Co-Pay Card Program
DESCRIPTION: Help qualified patients with the out-of-pocket costs associated with their Pulmozyme® (dornase alfa) Inhalation Solution prescription.
WEBSITE: www.pulmozymecopaycard.com
PHONE: (877) PZ4URCF/(877) 794-8723

GILEAD

PROGRAM: Cayston® Access Program
DESCRIPTION: A counseling and support program that assists patients with reimbursement and access to Cayston.
WEBSITE: https://www.cayston.com/cayston-access-program.html
PHONE: 1-877-7CAYSTON (1-877-722-9786)

J & J HEALTHCARE SYSTEM

PROGRAM: J & J Healthcare Patient Assistance Program
DESCRIPTION: Assists patients without adequate financial resources and

prescription coverage in obtaining free products donated by the operating companies of Johnson & Johnson.
WEBSITE: http://www.jjpaf.org/
PHONE: 1-800-652-6227

NOVARTIS PHARMACEUTICALS

PROGRAM: TOBI CARE Patient Assistance Program

DESCRIPTION: Designed to provide patients with all the support they need in one place; including a $10 co-pay program, co-pay assistance foundations, and a patient assistance program.
WEBSITE: http://www.tobitime.com/info/tobi-care-support/tobi-care-support-program.jsp
PHONE: 1-877-999-TOBI (8624)

PROGRAM: PodCare+™

DESCRIPTION: A customized support program that can save you time by working with your insurance company and helping you find the right Specialty Pharmacy; connect you with registered nurses who can answer your questions about TOBI Podhaler treatment; save you money by providing co-pay support and assistance with insurance reimbursement to reduce out-of-pocket costs; and coordinate timely refills of your TOBI Podhaler.
WEBSITE: https://www.tobipodhaler.com/getting_tobi_podhaler.jsp
PHONE: 1-888-669-6682

NOVO NORDISK

PROGRAM: Cornerstones4Care™ Patient Assistance Program

DESCRIPTION: The Diabetes PAP provides free medicine to those who qualify. If approved, a free 90-day supply of medicine will be sent to the prescribing healthcare providers' office to be picked up at the patient's convenience.
WEBSITE: http://www.cornerstones4care.com/
PHONE: 1-866-310-7549

MERCK

PROGRAM: Multi-use savings coupon for NASONEX.

DESCRIPTION: Eligible patients may save up to $15 off on each of up to 6 qualifying prescriptions of NASONEX.
WEBSITE:
www.nasonex.com/nasx/specialOffers.action?link=personalizedProgram&web_program_id=00000000
PHONE: 1-877-264-2440

SUNOVION PHARMACEUTICALS

PROGRAM: $20 Off Coupon for your next Xopenex HFA® Prescription.
DESCRIPTION: Qualifying patients will receive up to $20 off their Xopenex HFA prescription, benefit not to exceed out-of-pocket costs.
WEBSITE: https://secure.xopenex.com/xopenexPromos/eligibility.cfm
PHONE: 1-888-204-1754

VERTEX

PROGRAM: Kalydeco GPS: Guidance & Patient Support
DESCRIPTION: This resource provides support services to patients including education, reimbursement support, and live assistance by phone.
WEBSITE: www.vertexgps.com/kalydeco/patient/kalydeco-gps-call-center
PHONE: 1-877-7KALYDECO (1-877-752-5933)

MEDICATIONS & TREATMENTS

There is no cure for cystic fibrosis, but treatment can ease symptoms and reduce complications. Close monitoring and early, aggressive intervention is recommended.

Managing cystic fibrosis is complex, so consider obtaining treatment at a center that specializes in cystic fibrosis. These care centers partner with people with CF to develop individual treatment plans that typically include high-calorie, high-fat diets, therapies to loosen the clogged mucus from their airways, and mucus-thinning drugs and antibiotics when needed.

The goals of treatment include:

- Preventing and controlling lung infections
- Loosening and removing mucus from the lungs
- Preventing and treating intestinal blockage
- Providing adequate nutrition

Information provided by the Mayo Clinic: http://www.mayoclinic.com/health/cystic-fibrosis/DS00287/DSECTION=treatments-and-drugs

People with cystic fibrosis (CF) have more therapy options than ever before, including a recent breakthrough therapy that addresses the underlying cause of CF. As technology continues to advance, hopefully a cure is not too far away.

For a timeline of CF research milestones, visit the Cystic Fibrosis Foundation's website: http://www.cff.org/research/ResearchMilestones/

For information on how to participate in clinical trials, visit the Cystic Fibrosis Foundation's website: http://www.cff.org/research/ClinicalResearch/FAQs/

To learn about clinical trials available for cystic fibrosis, search on the National Institutes of Health website: www.clinicaltrials.gov

ANTIBIOTICS

An antibiotic is a term for a drug or other substance used to kill or slow the growth of bacteria that can cause infection. These drugs are used both to treat current infections and to prevent future infections. Because most CF patients are prone to lung infections, the antibiotics are nebulized and inhaled. This method localizes the antibiotic, so the rest of the body is not exposed to unnecessary drugs.

Inhaled Antibiotics

Cayston®

Cayston is the brand name for the antibiotic aztreonam. This antibiotic is used to treat common infections in CF patients, especially *Pseudomonas aeruginosa*. It interferes with the synthesis of bacterial cell walls, which leads to death of the bacteria. Cayston is dosed at 75 mg, given three times daily via the Altera® nebulizer. Common side effects include cough, nasal congestion, and throat irritation.

**Foundation Care is one of four pharmacies partnered with Gilead to make this product available to patients.*

Colistimethate

Colistimethate is commonly used to prevent and treat infections caused by resistant bacteria like *Pseudomonas aeruginosa*. It interrupts the cell membrane of bacteria, leading to death of the organism. Typical doses of colistimethate are 75-150 mg nebulized twice daily, depending on what kind of nebulizer a patient uses. Common side effects of inhaled colistimethate include bronchospasm and shortness of breath, which may be alleviated with use of a bronchodilator prior to nebulizing colistimethate. Rarely, it can cause kidney damage and hearing disturbances.

Tobramycin

- **TOBI®**

(Tobramycin Inhalation Solution) TOBI 300 mg/5 ml is the brand name for the antibiotic tobramycin. It is one of the main antibiotics used in CF patients in the United States. It works to treat infections of the lung caused by *Pseudomonas aeruginosa* by interrupting protein synthesis of bacterial cells.

- **BETHKIS®** *Coming soon!*

(Tobramycin Inhalation Solution) is indicated for the management of cystic fibrosis patients with Pseudomonas aeruginosa. It offers a concentrated solution, delivering 300 mg of nebulized tobramycin in only 4 mLs. The solution offers osmolarity similar to that of airway surface liquid in patients with cystic fibrosis.

- **TOBI® Podhaler™**

(Tobramycin Inhalation Powder) is a plastic, handheld inhaler device, which contains a dry powder formulation of tobramycin, an antibiotic used to treat P. aeruginosa infection. The powder is inhaled twice daily using the Podhaler device for 28 days. Patients should then stop TOBI Podhaler therapy for 28 days before resuming again.

Compounded Antibiotics

Many compounded antibiotics for inhalation are available at Foundation Care that are not available at other pharmacies. Foundation Care has the resources to provide CF patients with customized medications to aid in preventing and treating infections (as prescribed by a physician).

To view a list of available compounds at Foundation Care, please visit

www.FoundCare.com/fc-patients/compounding-customized-unit-dose-medications/

ANTI-INFLAMMATORY

Anti-inflammatory drugs help reduce inflammation or swelling of tissues in the body. People with CF have inflammation in their lungs. This is one cause of lung damage.

Azithromycin

Azithromycin is an antibiotic that reduces inflammation by inhibiting pro-inflammatory mediators and preventing neutrophil migration. It also prevents pulmonary infections such as pneumonia that are caused by common and atypical microorganisms. In patients with CF, it is mostly used for its anti-inflammatory properties.

Typical doses in patients with CF are 250-500 mg orally three times per week. No dose adjustments are needed in patients with liver or kidney dysfunction.

Common side effects include stomach upset and diarrhea. Azithromycin rarely causes liver dysfunction, allergic reactions, and QT interval prolongation. The risk for QT interval prolongation is increased in patients who are elderly and when azithromycin is given with certain other drugs, such as thioridazine and some anti-arrhythmic agents.

Budesonide

Budesonide is a corticosteroid. It works by preventing or reducing inflammation in the lungs. Inhaled budesonide and other corticosteroids may be used for CF patients with other medicines such as bronchodilators, which are also used to open up narrowed breathing passages in the lungs.

The Cystic Fibrosis Foundation guidelines do not recommend routine inhaled steroid use in patients with CF because these drugs impair the immune system, but in certain patients steroids may be beneficial.

Typical doses of budesonide are 0.25-0.5 mg twice daily via nebulizer. Side effects may include nausea, headache, sinus irritation, respiratory infection, and nosebleed.

Ibuprofen

Ibuprofen belongs to a class of drugs called non-steroidal anti-inflammatory drugs, or NSAIDs. It works by reducing inflammation of the airways and lungs of CF patients. It does this by preventing the synthesis of certain inflammatory molecules called prostaglandins. Ibuprofen slows the progression of lung destruction and is recommended for most patients with CF who are between the ages of 6-17 years old.

Ibuprofen is dosed based on weight in CF patients and blood levels should be monitored to ensure the drug is reaching high enough levels. Common side effects include stomach upset and nausea. Rarely, ibuprofen can cause blood disorders, kidney dysfunction, and stomach ulcers. These rare events occur more frequently with long-term use.

Ibuprofen should not be used with any other NSAID, including naproxen (Aleve®), meloxicam (Mobic®), and nabumetone (Relafen®).

BRONCHODILATORS

Bronchodilators help open the airways in the lungs by relaxing smooth muscle around the airways.

Albuterol

Albuterol is available in multiple forms, but the most common preparations are nebulizer solutions and metered-dose inhalers. Common side effects include restlessness or nervousness, tremor, headache, and tachycardia (rapid heart rate).

Products include:

- Albuterol nebulizer solution
- ProAir® HFA inhaler
- Ventolin® HFA inhaler

Levalbuterol

Levalbuterol is structurally similar to albuterol and causes relaxation of the airways. Levalbuterol was originally thought to cause fewer side effects than albuterol, but it remains controversial whether there truly is a difference. This medication is currently not available in the generic form, so it likely will be more expensive than albuterol. Common side effects include restlessness or nervousness, tremor, tachycardia, rhinitis (nasal inflammation), and headache.

Products include:

- Xopenex Nebulizer Solution
- Xopenex HFA® inhaler

Please Note*: Albuterol and levalbuterol should **not be used simultaneously.

Ipratropium

Ipratropium works by relaxing the muscles surrounding the airways and it prevents or reduces mucus secretions from certain glands. It is available in combination with albuterol. The most common preparations used are the nebulizer solutions and the metered-dose inhalers. Common side effects include bronchitis, sinusitis, headache, dyspnea (difficulty breathing), and urinary tract infection.

Products include:

- Atrovent® HFA metered dose inhaler *(ipratropium bromide)*
- Duoneb® nebulizer solution *(ipratropium bromide and albuterol)*
- Combivent® metered dose inhaler *(ipratropium bromide and albuterol)*
- Ipratropium bromide nebulizer solution

Valved Holding Chambers and Spacers

In order for inhaled asthma medicines to work properly, they need to reach your lungs. By simply attaching a valved holding chamber or spacer to your metered-dose inhaler, you can:

- Help the medicine move past your mouth and throat and get deep into your lungs where it can do its work
- Avoid problems with spraying and breathing at the same time
- Keep you from breathing the medicine in too fast
- Make it easier to take your medicine when you are having asthma symptoms
- Valved holding chambers and spacers are very similar devices; both are plastic tubes that attach to your metered-dose inhaler and are recommended for adults and children.

CFRD: CYSTIC FIBROSIS RELATED DIABETES

Diabetes is a very common complication that develops over time in many people with cystic fibrosis (CF). In fact, most adults living with CF have some degree of diabetes or glucose intolerance. Cystic fibrosis—related diabetes (CFRD) is a unique type of diabetes that only people with cystic fibrosis can get. However, it is important to know that not all CF patients will develop cystic fibrosis related diabetes (or CFRD). CFRD is similar to, but not the same as, diabetes in people who do not have cystic fibrosis. Consequently, treatment of CFRD is not the same as treatment of other types of diabetes.

Information found at http://cysticfibrosis.about.com.

Treatments

Insulin

Insulin is the medication used to treat CFRD. It allows sugars and proteins to move from the blood into the body's cells. It is used for energy and to build muscle. Keeping blood glucose levels at a normal or near-normal level helps you gain weight, feel better and have more energy. It also lowers the risk of problems caused by diabetes.

There are several types of insulin available. They differ in how fast they start to work and how long they work in the body to control blood sugar. Products include:

Rapid- acting	Humalog®, Novolog®, Apidra®
Short-acting	Humulin R®, Novolin R®
Intermediate-acting	Humulin N®, Novolin N®
Long-acting	Levemir®, Lantus®
Combinations	Novolog Mix®, Humalog Mix®, Novolin®

Using too much insulin can result in hypoglycemia (low blood sugar). Common symptoms of hypoglycemia: shakiness, dizziness or lightheadedness, sweating, headache, and weakness.

Metformin

Our bodies use sugar (also called glucose) as a source of energy to help us with our normal activities throughout the day. Patients with diabetes have more sugar in their blood which can cause damage to healthy areas of the body. Metformin works in three different ways to lower the amount of sugar found in the blood:

1. Decreases the amount of sugar that makes it into the blood from the food.
2. Helps our bodies to better use the excess sugar that enters into the bloodstream.
3. Decreases the amount of sugar that is produced by the liver.

Common side effects: diarrhea, upset stomach, nausea, and vomiting. It is important to note that most side effects will resolve within a few weeks of taking the medication at its optimal dose. Taking the medication with meals will help to minimize side effects.

Devices

Glucometers

In patients with CFRD, great care must be taken to monitor blood sugar levels. Glucometers are devices that allow patients and healthcare providers to monitor blood sugar (glucose) levels. Examples of brand name glucometers include:

- Accu-chek
- Bayer Breeze
- Freestyle Lite
- One Touch Ultra

COMPOUNDED MEDICATIONS

Most people would describe the medication they take as being made by a drug manufacturer in a manufacturing plant or factory. In fact, this is correct for the majority of prescription medications. Sometimes though, manufactured medications cannot meet the needs of certain patients.

Examples of these situations include:

- A child needs a medication in a liquid form, but it only comes as a capsule.
- A patient needs a medication that is no longer manufactured.
- A patient needs a dose that is not commercially available.
- The commercially available product is not available.
- A patient is allergic or cannot tolerate an ingredient in a commercial product.
- A medication needs to be customized to be delivered through a specific nebulizer.

Where To Find Compounded Medications

Compounding is the mixing of drugs by a compounding pharmacist. Pharmacists prepare compounded drugs in a licensed pharmacy. Pharmacies vary in the training, skills and capabilities of their staff; whereas a particular pharmacy may be able to prepare one type of compound, it may not be equipped to prepare another type.

Pharmacy Compounding Accreditation Board (PCAB)

While all pharmacies must meet licensure requirements, PCAB accredited pharmacies have gone the extra mile to demonstrate that they comply with nationally accepted quality control, quality assurance and quality improvement standards. This helps assure that the patient receives a quality medication. In order to demonstrate compliance with PCAB standards and earn PCAB accreditation, pharmacies voluntarily participate in an evaluation process that includes:

- Verification by PCAB that the pharmacy is not on probation for issues related to compounding quality, public safety or controlled substances.
- Verification that the pharmacy is properly licensed in each state it does business in.
- An extensive on-site evaluation by a PCAB surveyor, all of whom are compounding pharmacists trained in evaluating compliance with PCAB's quality standards. This evaluation includes:
    - An assessment of the pharmacy's system for assuring and maintaining staff competency.
    - A review of facilities and equipment.
    - Review of records and procedures required to prepare quality compounded medications.
    - Verification that the pharmacy uses ingredients from FDA registered and or licensed sources.
    - Review of the pharmacy's program for testing compounded preparations.

Only when a pharmacy has met PCAB's rigorous standards, is accreditation issued. PCAB accreditation means the pharmacy has independent, outside validation that it meets nationally accepted quality assurance, quality control, and quality improvement standards. When choosing a compounding pharmacy, PCAB suggests looking for the designation "PCAB Accredited® compounding pharmacy" or the PCAB Seal.

Examples of Compounded Medications for Nebulization

- Amikacin
- Amphotericin B
- Ceftazidime
- Ciprofloxacin
- Clindamycin
- Colistimethate
- Gentamicin
- Levofloxacin
- Pentamidine
- Tobramycin
- Vancomycin

**Information courtesy of PCAB. To learn more about compounding, visit:* http://www.pcab.org/consumers

GENE THERAPY

Gene therapy is an experimental technique that uses genes to treat or prevent disease. In the future, this technique may allow doctors to treat a disorder by inserting a gene into a patient's cells instead of using drugs or surgery. Although gene therapy is a promising treatment option for a number of diseases, the technique remains risky and is still under study to make sure that it will be safe and effective.

Products

KALYDECO

KALYDECO (ivacaftor) is a prescription medicine used for the treatment of cystic fibrosis (CF) in patients age 6 years and older who have a certain mutation in their CF gene called the G551D mutation. It works to restore proper function to the CFTR protein.

KALYDECO is not for use in people with CF due to other mutations in the CF gene. It is not effective in CF patients with two copies of the F508del mutation (F508del/F508del) in the CF gene.

KALYDECO is supplied as 150 mg tablets. The usual dose is one tablet by mouth every 12 hours. The tablet should be taken with fat-containing food to increase absorption, and should not be taken with grapefruit or Seville oranges. Common side effects may include stomach upset, rash, headache, and throat irritation. Rarely, liver enzymes may be increased by KALYDECO.

It is not known if KALYDECO is safe and effective in children under 6 years of age.

For more information, visit: http://www.kalydeco.com/

KALYDECO was named the most important new drug of 2012 by Forbes.
http://www.forbes.com/sites/matthewherper/2012/12/27/the-most-important-new-drug-of-2012/

CF Mutation Analysis Program (MAP)

The Cystic Fibrosis Mutation Analysis Program (MAP) is a valuable program that provides free genotyping and follow-up testing as needed for people with cystic fibrosis.

The MAP is only available to patients with cystic fibrosis. Utilization of the program will help CF patients identify which CFTR mutation they have.

Once the patient's mutation is identified, the patient and provider can make informed decisions about the appropriate treatment options.

The Cystic Fibrosis Foundation will cover the cost of the genotyping. However, the patient or CF care center is responsible for the cost of the blood sample, and shipping and postage for mailing the sample to the lab.

For more information about MAP, please visit the CF Foundation's website:
http://www.cff.org/LivingWithCF/AssistanceResources/MAP/

MUCUS CLEARANCE

People with cystic fibrosis do airway clearance techniques (ACT) to loosen and get rid of the mucus from the lungs. Clearing mucus helps to reduce the severity of lung infections and improve lung function. Inhaled drugs are commonly used in cystic fibrosis care because they reach the airways quickly and make it easier to cough out the mucus.

Acetylcysteine

When acetylcysteine is inhaled, it breaks down the mucus in the lungs and lowers the viscosity of the mucus. This makes it easier to expel the mucus when coughing and huffing. Common side effects include drowsiness, nausea, vomiting, fever, rhinorrhea, and bronchospasm.

Products include:

- Acetylcysteine inhalation solution 10% (100mg/mL)
- Acetylcysteine inhalation solution 20% (200mg/mL)
- Preservative-Free Acetylcysteine inhalation solution 10% (100mg/mL)
- Preservative-Free Acetylcysteine inhalation solution 20% (200mg/mL)

Hypertonic Saline

Hypertonic saline (HS), or sodium chloride, is any salt-water solution that contains a greater concentration of salt than our body fluids. The HS draws water from the cells into the airway. The water mixes with the thick mucus in the airway, making it thinner and easier to cough out. HS used in cystic fibrosis usually starts at 7%, but products can be compounded to different concentrations, if needed. Common side effects nausea and vomiting, bronchospasm, pulmonary edema, and transient hypotension.

Products include:

- HyperSal® (7%)
- Hypertonic Saline (3%, 4%, 5%, 6%, 7%)

Pulmozyme® (dornase alpha)

The thick mucus in the airways which is associated with cystic fibrosis contains a high concentration of deoxyribonucleic acid (DNA). When nebulized, Pulmozyme® works within the cells of the lung to break down the DNA that causes thick mucus to build up. This thins the mucus, making it easier to expel, while also helping to decrease the frequency of respiratory infections. Common side effects include fever, pharyngitis, rhinitis, chest pain, and rash.

Products include:

- Pulmozyme® 1 mg/mL inhalation solution

NASAL THERAPIES

Nasal irrigation is an excellent way to clean mucus from the nose making medication more effective. It can clean allergens, irritants, bacteria and viruses from the nose reducing the frequency of infection. It can also help decrease swelling in the nose and increase air flow.
Furthermore, nasal and sinus medication delivery devices are clinically shown to deposit medication throughout the nasal and paranasal sinus cavities.
**Pharmacies like Foundation Care can work with your physician to customize medication dosage forms to specific devices and patient needs.*

Examples of Products Include:

Sinus Rinse™ Extra Strength Hypertonic Packets

Sinus Rinse™ is a natural soothing saline nasal wash. A large volume low positive pressure nasal wash is the most effective way to irrigate the nose based on current medical studies. Nasal Irrigation is an excellent way to clean mucus from the nose making medication more effective. They also clean allergens, irritants, bacteria and viruses from the nose reducing the frequency of infection. Furthermore, they help decrease swelling in the nose and increase air flow. Sinus Rinse™ is available in isotonic, pediatric and hypertonic concentrations.

Nasopure® Nasal Wash

The Nasopure® Nasal Wash Bottle is patented and designed to wash the nose efficiently and comfortably. The unique, angled neck allows a neutral head and neck position to achieve the perfect wash. The squeezable, plastic bottle provides precise control of the solution from a light rinse to a steady flush. The applicator tip allows for a tight seal with the nostril for control of pressure and flow. It washes the nasal membranes, while drawing out the sinus contents as the solution exits the opposite nostril.

Neil-Med Sinus Rinse Kit

Sinus Rinse™ is a natural soothing saline nasal wash. A large volume low positive pressure nasal wash is the most effective way to irrigate the nose based on current medical studies. Sinus Rinse™ is available in isotonic, pediatric and hypertonic concentrations.

NasoNeb®

The NasoNeb® Nasal Nebulizer delivers a deep, penetrating aerosol to the nasal and paranasal sinus cavities with virtually no incidental pulmonary delivery of drugs and the risk of resultant complications common with small particle nebulizers. With NasoNeb-delivered therapies, side effects associated with cold medicated irrigations may also be avoided.

PARI Sinus Nebulizers and Medication Delivery Devices

- **Sinus™ Pulsating Aerosol System**

The PARI Sinus™ Pulsating Aerosol System combines efficient nebulization with a vibrating pulse, delivering aerosol directly to the sinuses. Aerosol therapy has been used effectively to treat upper airway conditions including chronic sinusitis, rhinitis, and allergies.

- **SinuStar™ Aerosol Delivery System**

PARI SinuStar™ is specifically designed for nasal and intranasal delivery of aerosol. PARI SinuStar™ directs aerosol toward the upper airway and produces small particles that can easily navigate the nasal cavity.

- **Montesol™ Nasal Wash**

The PARI Montesol™ Nasal Wash is a gentle and effective way to cleanse the nasal passages of: dust, dirt, and pollen, airborne allergens, excess mucous, and crust associated with post-operative nasal and sinus surgery.

SINOFRESH

SINOFRESH Nasal & Sinus Care is a homeopathic nasal spray containing eucalyptus globulus and kalium bichromicum. While keeping the noise moist, SINOFRESH eliminates sinus discomfort at its source, without side effects. It kills germs and mold, is non-addictive and has no drug interactions.

NUTRITION

An important factor for staying healthy is good nutrition. Thick mucus often gets in the way of proper digestion, causing malabsorption. This problem is treated with pancreatic enzyme supplements, vitamins and a high-calorie, high-fat diet. By following a treatment plan developed with their CF care center team, many people with CF can slow down the progression of their disease.

Pancreatic Enzymes

Mucus buildup associated with CF can cause the pancreas to not work as it should causing Pancreatic Insufficiency. Pancreatic enzymes, also known as pancrelipase, contain enzymes from the pancreas called lipase, amylase, protease and others. These enzymes break down food in the GI tract. Taking enzymes helps improve overall nutrition and helps maintain a healthy body weight in CF patients.

Products include:

- Creon®
- Pancrelipase™
- Pancreaze®
- Pertzye™
- Ultresa™
- Viokace™
- Zenpep®

Vitamins

Many multivitamins are available for CF patients that provide essential fat-soluble vitamins A, D, E, and K. These vitamins must be supplemented because CF patients are unable to absorb them from the GI tract, which can lead to malnutrition, osteoporosis, and infections.

Multivitamins include:

- AquADEKs®
- ChoiceFul™

Other vitamins:

- Replesta™ (Vitamin D supplement)

Therapeutic Drink Supplements

Drinks containing calories, protein and fiber to help gain weight, strength, energy, build muscles and maximize a person's ability to recover.

Products include:

Boost®	*Nutritional shakes in a variety of flavors and formulations such as strawberry, chocolate, vanilla, gluten-free, and lactose-free. Each Boost Plus® drink contains approximately 360 calories. For more information visit their website: www.boost.com*
Opt2Thrive™	*A delicious therapeutic supplement for anyone age 2 thru 102 who is having difficulty gaining weight due to a variety of illnesses, diseases, and conditions. Each 9 oz. contains approximately 630 calories. For more information visit their website: www.opt2thrive.com*
ScandiShake®	*Available in chocolate, vanilla, strawberry, lactose-free, and gluten-free. When mixed with 8 oz. of whole milk, each shake contains approximately 600 calories. For more information visit their website: www.aptalispharma.com/en/us_scandishake*

TRANSPLANTS

Lung Transplants

When someone with CF develops severe lung disease, the CF care team may discuss the option of lung transplantation with the person. Most CF care teams will begin discussing transplant as an option *before* it becomes necessary. The doctor can refer the person to a lung transplant center for evaluation. The transplant center then discusses the overall process of testing and waiting for transplant, as well as the surgery itself, survival statistics as well as the post-transplant care.

Evaluation Process

The person's health is looked at to find out if a lung transplant is necessary and timely. These tests look at how well the lungs, heart and kidneys work, the types of germs in the lungs and, because of the seriousness of transplantation, the person's psychological wellbeing. The transplant center will also evaluate the person's social support system, including family and friends, and whether professional support services may be needed during transplant. Most of the evaluation is standard, but each center can have some specific requirements. The staff's decision to accept a person for a transplant is specific to that center.

Statistics

Almost 1,700 lung transplants were performed in 2011 in the United States; this number has been steadily rising throughout the years. According to the CF Foundation Patient Registry, nearly 2,800 people with CF have received lung transplants since 1990. In the last 5 years, about 150 to 200 people with CF have received lung transplants per year. While there is still a shortage of available organs, the number of people who die while waiting for transplant has declined dramatically in recent years. This is due to changes in the system of how it is decided who gets an organ. This is called an allocating system.

Does CF "*go away*"?

Transplanted lungs do not have CF because they come from people who do not have CF. However, after the transplant, the person still has CF in the sinuses, pancreas, intestines, sweat glands and reproductive tract. The new lungs do not "get" CF, but immunosuppressive drugs may decrease the ability to fight germs like Pseudomonas aeruginosa (Pseudomonas) and Burkholderia cepacia complex (B. cepacia). These germs may stay in the upper airways after a transplant and can infect the new lungs. The risks of infection are highest right after the transplant operation. This is because immunosuppressive drugs are given at the highest doses right after the transplant so the body will not reject the new lungs. These drugs make it hard for the body to fight infections, and this can lead to lung infections.

For More Information, Visit: http://www.cff.org/treatments/LungTransplantation/

Transplant Grants: http://esiason.org/thriving-with-cf/transplant-grants.php

While the cost of transplantation is typically covered by most insurance companies, travel and relocation costs are typically absorbed by the patient's families. The Boomer Esiason Foundation Lung Transplant Grant Program is one way the Foundation works to give back to people with CF in the here and now, by helping families pay for the expenses that are not covered by their insurance.

Encourage Donors

Ask your friends and family to register as organ donors! Go to www.DonateLife.net to find out more.

NEBULIZERS

A typical Cystic Fibrosis (CF) patient's daily therapy includes inhaled aerosolized medications, as many suffer from chronic infection of the airways.

To deliver these medications, a device known as a nebulizer must be used to break down the liquid medication into aerosol mist that can be inhaled through a mouthpiece or face mask. Similar to inhalers, these devices deliver medication straight into the lungs by simply inhaling the mist.

There are a variety of different nebulizers available for use. The differences between nebulizers include:

- Size
- Shape
- Portability
- Treatment length
- Noisiness
- Efficiency of medication delivery

In general, nebulizer treatment durations may range from 15 to 40 minutes per drug. Due to the respiratory complications of CF, patients are usually prescribed several aerosolized medications. A CF patient may have as many as 4 or 5 different aerosolized medications that may need to be administered as often as two to three times a day.

ACCESSORIES

Masks

- Designed to make treatments more comfortable for those who are used to masks.
- Alternative for people who have difficulty using nebulizer mouthpiece inhalers.
- Most pediatric masks are animal-themed to make nebulizer treatments fun for kids!

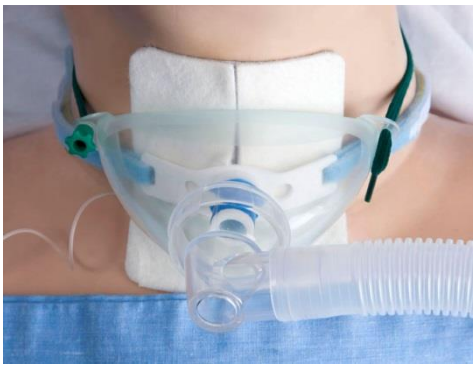
People with lung conditions often rely on certain medications to help treat these diseases or alleviate symptoms. Oftentimes, a doctor will prescribe a nebulizer for the patient to use, making the medications easier to inhale. In order to receive the medication in this form, a patient may use a nebulizer mask.

A nebulizer mask is usually made out of rubber or clear vinyl. It consists of a mask that fits over the patient's nose and an adjustable elastic strap that fits around the head to keep the mask in place. Pediatric nebulizer masks for children also come in a variety of character shapes, such as dinosaurs or fish, to make children more comfortable using them.

For Tracheostomy Patients

A tracheostomy is a small opening through the skin in your neck into the windpipe (trachea). A small plastic tube, called a tracheostomy tube or trach tube, is placed through this opening into the trachea to help keep the airway open. A person breathes directly through this tube, instead of through the mouth and nose.

For CF patients with a tracheostomy, nebulization cannot take place the normal way. Instead, these patients connect aerosol tubing between a trach mask and the oxygen source. Then the mask's elastic strap is positioned behind the neck and pulled gently at the ends until the trach mask is secure.
**Information found at: http://www.mountainside-medical.com/products/Tracheostomy-Mask-(Adult).html*



ALTERA® ELECTRONIC NEBULIZER

Product Facts

The Altera Nebulizer System is intended specifically for the aerosolization of CAYSTON (aztreonam for inhalation solution) using vibrating membrane technology. The device is intended for adult and pediatric patients who have been prescribed CAYSTON, and may be used in hospitals, hospital-type facilities, nursing homes, sub-acute institutions and home environments.

The Altera Nebulizer System uses eFlow Technology to enable highly efficient aerosolization of medication via a vibrating, perforated membrane that includes thousands of small holes producing the aerosol mist. Compared to other nebulization technologies, eFlow Technology produces aerosols with a very high density of active drug, a precisely defined droplet size, and a high proportion of respirable droplets delivered in the shortest possible period of time.

The Altera was **designed only to deliver doses of Cayston. Utilizing other medications in the device will invalidate the device's warranty and may deliver inaccurate doses to the patient.*

Product Benefits

- Approved by the FDA in February 2010
- Designed to nebulize Gilead Science's CAYSTON only
- Handheld device
- Uses eFlow technology
- Medicine is nebulized in less than five minutes
- Designed to be used with "AA" batteries or with the optional AC Power Supply
- First drug-specific nebulizer for use in the treatment of patients with cystic fibrosis

Contact

Gilead Headquarters:
333 Lakeside Drive
Foster City, CA 94404
Phone: (650) 574-3000
Fax: (650) 578-9264
1-800-GILEAD-5 (1-800-445-3235)

Website: https://www.cayston.com/about-cayston/altera-nebulizer-system.html

**All information on this page was found on Cayston's official website at www.cayston.com.*

eRAPID™ NEBULIZER SYSTEM

Product Facts

The eRapid™ Nebulizer System is a handheld nebulizer used with patients for whom doctors have prescribed medication for nebulization. It is intended for adult and pediatric patients, and may be used in hospitals, hospital-type facilities, nursing homes, sub-acute institutions and home environments.

Product Benefits

- Short treatment times encourage patient adherence.
- Quiet operation for discrete use.
- Light, compact and portable.
- Flexible power options including off the shelf batteries, rechargeable batteries, or AC wall power.
- Two (2) complete nebulizer handsets to alternate or use while traveling.
- eBase™Controller provides patient with feedback including battery life, proper assembly, medication loading, and end of treatment.
- Can be disinfected in steam disinfector.
- Can be disinfected by boiling in distilled water.
- Autoclavable (up to 121° C).

Please Note:

*Studies comparing the eRapid with the Pari LC® Plus suggest that *in healthy individuals,* the two devices are comparable. However, *in CF patients* the eRapid delivered 40% less medication than the LC Plus. Also, more medication remained in the eRapid after each treatment.
*The Trio® delivers drug into the lungs more efficiently, allowing a patient to use a lower dose of medication. This, in turn, could help lower the overall cost of the patient's care. Also, the Trio® essentially wastes no medication and nebulizers virtually every drop of medication placed in the handset reservoir.
*Currently, the only available studies for the eRapid compare the device to older, jet nebulizer technology.

SOURCES:

Hubert D, Leroy S, Nove-Josserand R, Murris-Espin M, Mely L, Dominique S, et al. Pharmacokinetics and safety of tobramycin administered by the PARI eFlow® rapid nebulizer in cystic fibrosis. Journal of Cystic Fibrosis; Vol 8, August 2009, pp 332-337.
Hubert D, Leroy S, Nove-Josserand R, Murris-Espin M, Mely L, Dominique S, et al. Pharmacokinetics and safety of tobramycin administered by the PARI eFlow®rapid nebulizer in cystic fibrosis. Journal of Cystic Fibrosis, August 2009, pp 332-337.
Lenney W, Edenborough F, Kho P, Kovaric JM. Lung deposition of inhaled tobramycin with eFlow rapid/LC Plus jet nebuliser in healthy and cystic fibrosis subjects. Journal of Cystic Fibrosis, October 2011, pp 9-14

Contact

PARI Respiratory Equipment, Inc.
2412 PARI Way
Midlothian, VA 23112
Tel: 1.800.FAST.NEB (327.8632)
Fax: 1.800.727.4112
Email: productinfo@PARI.com

Website: www.pari.com/products/erapidtm

**Product Facts and Benefits information were found on PARI's official website at: http://www.pari.com/products/erapidtm/product/detail/info/erapid_nebulizer_system.html*

PARI LC® D NEBULIZER

Product Facts

The PARI LC® D Disposable Nebulizer is used to deliver aerosolized medication to the lungs, with patients for whom a physician has prescribed medication for aerosol treatments in a home, doctor's office, hospital, or clinic environment.

The PARI LC® D Disposable Nebulizer is designed for disposable, single patient use for office and hospital visits.

- This product should be replaced at least every 15 treatments, or 15 days, whichever is first.
- This product is not heat resistant. It will deform if cleaned in the dishwasher, boiled, autoclaved or cold sterilized.
- Deformation and/or prolonged use can cause inadequate output, resulting in improper treatments.
- The tubing presents a strangulation hazard.

To reduce the risk of infection and illness:

1. Nebulizer for single patient use (one person) only. Do not share your nebulizer with other patients.
2. You must regularly disinfect the nebulizer between treatments. Failure to do so could lead to serious or fatal illness.

This product is **DISPOSABLE and is not intended for prolonged or extended use.*

Contact

PARI Respiratory Equipment, Inc.
2412 PARI Way
Midlothian, VA 23112
Tel: 1.800.FAST.NEB (327.8632)
Fax: 1.800.727.4112
Email: productinfo@PARI.com

Website: www.pari.com/products/nebulizers/

*All information on this page was found on PARI's official website at
http://www.pari.com/products/nebulizers/product/detail/info/manual/lc_d_disposable_nebulizer.html*

PARI LC® PLUS NEBULIZER

Product Facts

The nebulizer cup is the part of your aerosol delivery system that turns your liquid medication into a mist, or aerosol. PARI's reusable nebulizers are special because they are breath enhanced. This technology delivers more medication when you breathe in, and wastes less when you breathe out for the best treatment possible.

Product Benefits

Exclusive to PARI, Timestrip® is an easy to use visual indicator that monitors time elapsed from a patient's first treatment to 6 months. No more guess work or hassle with calendars - Timestrip® clearly instructs patients to replace their PARI reusable nebulizer every 6 months.

- Easy to use and activate
- Great for Patient Reminder programs

Benefits of replacing PARI nebulizers:

1. Consistent medication delivery
2. Fast treatment times
3. Reduces the risk for bacterial contamination delivering fast, efficient treatments and optimal particle size.

Contact

PARI Respiratory Equipment, Inc.
2412 PARI Way
Midlothian, VA 23112
Tel: 1.800.FAST.NEB (327.8632)
Fax: 1.800.727.4112
Email: productinfo@PARI.com

Website: www.pari.com/products/nebulizers/

**All information on this page was found on PARI's official website at*
http://www.pari.com/products/nebulizers/product/detail/info/lc_plus_reusable_nebulizer.html

PARI LC® SPRINT NEBULIZER

Product Facts

The fastest of the PARI breath enhanced reusable nebulizers, delivering a consistent particle size for targeted delivery to the lungs while wasting less medication.

The nebulizer cup is the part of your aerosol delivery system that turns your liquid medication into a mist, or aerosol. PARI's reusable nebulizers are special because they are breath enhanced. This technology delivers more medication when you breathe in, and wastes less when you breathe out for the best treatment possible.

Product Benefits

Exclusive to PARI, Timestrip® is an easy to use visual indicator that monitors time elapsed from a patient's first treatment to 6 months. No more guess work or hassle with calendars - Timestrip® clearly instructs patients to replace their PARI reusable nebulizer every 6 months.

- Easy to use and activate
- Great for Patient Reminder programs

Benefits of replacing PARI nebulizers:

1. Consistent medication delivery
2. Fast treatment times
3. Reduces the risk for bacterial contamination

Contact

PARI Respiratory Equipment, Inc.
2412 PARI Way
Midlothian, VA 23112
Tel: 1.800.FAST.NEB (327.8632)
Fax: 1.800.727.4112
Email: productinfo@PARI.com

Website: www.pari.com/products/nebulizers/

**All information on this page was found on PARI's official website at http://www.pari.com/products/nebulizers/product/detail/info/lc_sprint_reusable_nebulizer.html*

PARI LC® STAR NEBULIZER

Product Facts

Designed for treating the deepest part of the lungs or for those patients with smaller airways due to age or advanced disease state.

The nebulizer cup is the part of your aerosol delivery system that turns your liquid medication into a mist, or aerosol. PARI's reusable nebulizers are special because they are breath enhanced. This technology delivers more medication when you breathe in, and wastes less when you breathe out for the best treatment possible.

Product Benefits

Exclusive to PARI, Timestrip® is an easy to use visual indicator that monitors time elapsed from a patient's first treatment to 6 months. No more guess work or hassle with calendars - Timestrip® clearly instructs patients to replace their PARI reusable nebulizer every 6 months.

- Easy to use and activate
- Great for Patient Reminder programs

Benefits of replacing PARI nebulizers:

1. Consistent medication delivery
2. Fast treatment times
3. Reduces the risk for bacterial contamination

Contact

PARI Respiratory Equipment, Inc.
2412 PARI Way
Midlothian, VA 23112
Tel: 1.800.FAST.NEB (327.8632)
Fax: 1.800.727.4112
Email: productinfo@PARI.com

Website: www.pari.com/products/nebulizers/

**All information on this page was found on PARI's official website at*
http://www.pari.com/products/nebulizers/product/detail/info/lc_star_reusable_nebulizer.html

MICRO MIST®

Product Facts

The Micro Mist is a high-performing nebulizer that delivers an optimal particle size at angles up to 90°. The unique design maximizes options for placement, without sacrificing aerosol quality. It is used for intermittent aerosol therapy and can be relied upon to deliver both performance and economy.

Product Benefits

- Optimal particle size delivered at efficient nebulization rates
- Consistent performance at angles up to 90 degrees allowing flexible medication delivery
- Jet stays in place unless intentionally removed
- Easy-seal, threaded cap and 6 cc capacity anti-spill jar to prevent leakage
- Recommended flow rate: 8 lpm
- Available with standard or universal tubing connector

Contact

Teleflex Medical
2917 Weck Drive
Research Triangle Park, NC 27709
Toll Free: 866-246-6990
Phone: 919-544-8000
Fax: 866-804-9881
cs@teleflex.com

Website: http://www.teleflex.com

**All information on this page was found on Teleflex's official website at:*
http://www.teleflex.com/en/usa/productAreas/respiratory/hudson-interactive-catalog/index.html

NASONEB® NASAL NEBULIZER

Product Facts

The NasoNeb® Nasal Nebulizer has been clinically-shown to deposit a low volume, high concentration of medication to the whole sinonasal region. Recent studies demonstrate that the NasoNeb System deposits medication to the whole sinonasal cavity, including the frontal recess/sinus, spheno-ethmoid recess, ethmoid cavity, sphenoid and maxillary sinuses, all turbinates, the middle meatus and olfactory cleft.

Product Benefits

Unlike previous delivery devices adapted from pulmonary nebulizers that generate small particles targeting the lungs *(as noted from The American Rhinologic Society Program: Annual Meeting 2010*), the NasoNeb System delivers large particles that are readily filtered by the nose to ensure a large percentage of medication is delivered to the target organ and that no drug is delivered to the lungs. These particles are delivered via a positive pressure airstream that coats the whole sino-nasal cavity with the medication.

Designed to mimic the spray pattern of an ENT powered atomizer, the NasoNeb Nasal Nebulizer is easy for the patient to use in their home, providing a comfortable mist that reaches the whole sino-nasal region.

Contact

1841 Buerkle Road
White Bear Lake, MN 55110
1-866-960-9833
1-651-236-8545
Fax: 1-651-748-8313
E-mail Us: customer.service@nasoneb.com

Website: www.nasoneb.com

**All information on this page was found on PARI's official website at http://www.nasoneb.com/index.php?page=nebulizer*

PARI PEP™ S

Product Facts

Positive Expiratory Pressure (PEP) device offers both traditional PEP therapy and combination PEP/Nebulizer therapy.

Positive Expiratory Pressure (PEP) is a type of therapy that creates resistance pressure during exhalation. PEP is used for airway stabilization and mucus clearance. PEP is recommend for patients diagnosed with Cystic Fibrosis or lung diseases with secretory problems.

Product Benefits

Designed for use with the PARI LC® Plus or LC® Sprint, combination therapy provides concurrent PEP therapy with clinically proven aerosol delivery. Shorter daily treatment regimens and clinically proven aerosol delivery result in an improved patient quality of life.

Benefits Include:

- Eight resistance setting covers a large expiratory flow range that offers pressure of 10-20cm of H_2O
- Dishwasher safe and boilable

Contact

PARI Respiratory Equipment, Inc.
2412 PARI Way
Midlothian, VA 23112
Tel: 1.800.FAST.NEB (327.8632)
Fax: 1.800.727.4112
Email: productinfo@PARI.com

Website: http://www.pari.com/products/accessories

**All information on this page was found on PARI's official website at http://www.pari.com/products/accessories_other/product/detail/info/pari_pep_s.html*

SINUSTAR™ AEROSOL DELIVERY SYSTEM

Product Facts

PARI SinuStar™ is specifically designed for nasal and intranasal delivery of aerosol. PARI SinuStar™ directs aerosol toward the upper airway and produces small particles that can easily navigate the nasal cavity. Aerosol therapy has been used effectively to treat chronic sinusitis, rhinitis, and allergies.

Product Benefits

Benefits of intranasal nebulized medication include:

- Direct topical administration for maximum rapid therapeutic effect.
- Minimal systemic side effects.
- Is now an accepted treatment option for patients who have not responded to oral or intravenous treatment.

Contact

PARI Respiratory Equipment, Inc.
2412 PARI Way
Midlothian, VA 23112
Tel: 1.800.FAST.NEB (327.8632)
Fax: 1.800.727.4112
Email: productinfo@PARI.com

Website: www.pari.com/products/sinus

**All information on this page was found on PARI's official website at http://www.pari.com/products/sinus/product/detail/info/sinustar_aerosol_delivery_system.html*

TRIO® ELECTRONIC NEBULIZER

Product Facts

The Trio® is an electronic handheld nebulizer used with adult or pediatric patients for whom doctors have prescribed medication for nebulization. The Trio reduces administration time by up to 50% vs a jet nebulizer when delivering equivalent respirable dose. It reduces the volume of drug necessary for treatments because of its high delivery efficiency.

Product Benefits

- Uses eFlow Technology
  - High delivery efficiency (delivered up to 90% of lung dose in less than half the time of a jet nebulizer)
  - Inhalation by spontaneous breathing
  - Fast treatments due to high output rate (.73 g/min)
  - Low residual dose (.3 mg)
- Increased freedom because an AC power source is not required
- Easy to clean and disinfect

Contact

SourceCF Inhalation Systems, UC,
a subsidiary of Aptalis Pharma US, Inc.
100 Somerset Corporate Boulevard
Bridgewater, NJ 08807
Phone: (888) 335-6946
Fax: (888) 419-8360
Trioinfo@aptalispharma.com

Website: http://www.sourcecf.com/

**All information on this page was found in Aptalis' Trio Pamphlet, "A Trio® of Benefits."*

AIRWAY CLEARANCE

Airway Clearance is the practice of stimulating the musculature of the lungs in order to break up thickened mucus trapped in small airways. This practice will allow patients to cough up the broken up mucus secretions with more efficiency and therefore help decrease the possibility of infection.

Respiratory health depends on consistent clearance of airway secretions. Normal airway clearance is accomplished by two important mechanisms: the mucociliary clearance (MCC) system and the ability to cough. Impaired MCC is linked to poor lung function in a broad range of diseases and disabilities.
Information provided by: http://www.thevest.com/airway-clearance/

Airway clearance techniques (ACTs) are treatments that help people with cystic fibrosis (CF) stay healthy and breathe easier. ACTs loosen thick, sticky lung mucus so it can be cleared by coughing or huffing. Clearing the airways reduces lung infections and improves lung function. There are many ACTs. Most are easy to do. For infants and toddlers, ACTs can be done by almost anyone. Older kids and adults can do their own ACTs.

ACTs are often used with other treatments, like inhaled bronchodilators and antibiotics. Bronchodilators should be taken before or with ACTs to open airways. Inhaled antibiotics should be taken after ACTs to treat opened airways. Your CF care team will help you choose the best ACT and other treatments. Each year, review and update your routine with your CF care team.
Information provided by http://www.cff.org/treatments/Therapies/Respiratory/AirwayClearance/

acapella® Vibratory PEP Therapy System

Combines the benefits of both PEP therapy and airway vibrations to mobilize pulmonary secretions and can be used in virtually any spatial orientation. Patients are free to sit, stand or recline.

Product Facts

- Improves clearance of secretions
- Easier to tolerate than CPT
- Takes less than half the time of conventional CPT sessions*
- Facilitates opening of airways in patients with lung diseases with secretory problems (COPD, asthma, Cystic Fibrosis)
- Color-coded units help customize treatment based on clinical needs *(green for high-flow, blue for low)*
- Adjust frequency and flow resistance simply by turning an adjustment dial

* Mahimeister MJ et al. "Positive-expiratory pressure mask therapy: Theoretical and Practical Considerations and a Review of the Literature", *Respiratory Care,* 1991.

Product Benefits

- Can accommodate virtually any patient's lung capacity.
- Allows inhalation and exhalation without removing from mouth.
- May be used with mask or mouthpiece.
- Use in any position - patient is free to sit, stand or recline.

Models

- acapella® duet
- acapella® choice
- acapella® DH (green)
- acapella® DM (blue)

Contact:

Smiths Medical North America
Tel: +1 800 258 5361 / +1 214 618 0218
info.asd@smiths-medical.com

Website: http://www.smiths-medical.com/catalog/bronchial-hygiene/acapella/acapella.html

**All information on this page was found on Smiths-Medical's official website at http://www.smiths-medical.com/catalog/bronchial-hygiene/acapella/acapella.html.*

CliniFLO® Low-Flow Incentive Spirometers

Ideal for therapy in geriatric, pediatric or weakened patients. With flow settings from 100ml/sec to 600ml/sec, virtually any patient can sustain the minimum inspiratory effort required for effective therapy.

Product Facts

- Slow inspirations enhance collateral ventilation and minimize patient discomfort when performing post-surgical breathing exercises.
- The 02 port makes it easy to provide oxygen during therapy.
- CliniFLO® unit comes with preassembled popple tubing, mouthpiece and instructions.

Product Benefits

- Can accommodate virtually any patient.
- Reduces the possibility of contamination.
- Provides immediate patient feedback.
- Easy to train.
- Reduces the chance that the setting will be changed inadvertently.

Contact:

Smiths Medical ASD, Inc.
160 Weymouth Street
Rockland, MA 02370 (USA)
Tel: (800) 848-1757
Fax: (800) 621-2950

Website: www.smiths-medical.com/respiratorycare

**All information on this page was found on Smiths-Medical's official website at http://www.smiths-medical.com/catalog/lung-expansion/insentive-spirometer/cliniflo-flow-based-incentive.html.*

COACH® 2 VOLUME INCENTIVE SPIROMETER

Coach® 2 Volume Incentive Spirometers

The one-way valve ensures patients inhale, rather than exhale into the unit and makes incentive spirometry easier for patients and staff alike.

Product Facts

A highly-visible piston, easy to understand graphics (indicating correct inspiratory flowrate), and instructions in the base, help patients perform and monitor their own post-surgical breathing exercises without direct supervision.

Other features include:

- 02 connection for supplemental oxygen
- Convenient handle
- Flexible popple tubing
- Bedrail holder

Product Benefits

- Ensures patients inhale, rather than exhale into the unit.
- Easily adjustable for each patient's use.
- Can be seen by patients emerging from the effects of anesthesia.
- Easy to train.
- Stays with the patient for maximum compliance.
- Accommodates patients requiring supplemental oxygen.
- Saves space.
- Colorful deep-sea characters, games, puzzles and stickers.

Contact:

Smiths Medical ASD, Inc.
160 Weymouth Street
Rockland, MA 02370 (USA)
Tel: (800) 848-1757
Fax: (800) 621-2950

Website: www.smiths-medical.com/respiratorycare

**All information on this page was found on Smiths-Medical's official website at http://www.smiths-medical.com/catalog/lung-expansion/insentive-spirometer/disposable-coach-spirometer.html.*

EzPAP® Positive Airway Pressure System

Lung expansion therapy to prevent or reverse atelectasis when incentive spirometry alone won't open patients' airways. *"The EASY option for atelectasis."*

Product Facts

System includes:

- The EzPAP® lung expansion device
- Mouthpiece
- Pressure port cap
- 7 feet of tubing
- Three mask options are also available

Product Benefits

- No equipment to roll around.
- No labor-intensive CPT.
- No extensive training.
- Just a few minutes as prescribed.

Contact:

Smiths Medical ASD, Inc.
160 Weymouth Street
Rockland, MA 02370 (USA)
Tel: (800) 848-1757
Fax: (800) 621-2950

Website: www.smiths-medical.com/respiratorycare

**All information on this page was found on Smiths-Medical's official website at http://www.smiths-medical.com/catalog/lung-expansion/ezpap-positive-airway-pressure/ezpap.html*

FLUTTER® Mucus Clearance Device

The FLUTTER® provides positive expiratory pressure (PEP) therapy for patients with mucus-producing respiratory conditions. This mucus clearance device is shaped like a pipe with a hardened plastic mouthpiece at one end, a plastic protective, perforated cover at the other end, and a high-density stainless steel ball resting in a plastic circular cone on the inside.

Product Facts

- When the patient exhales into the device, the ball rolls and moves up and down, creating an opening and closing cycle over a conical canal.
- The cycle repeats itself many times throughout each exhalation intending to produce oscillations of endobronchial pressure and expiratory airflow that will vibrate the airway walls and loosen mucus so that it can be easily expectorated by the patient.
- The vibrations produced by these oscillations cause the "fluttering" sensation from which the FLUTTER® derived its name.

Product Benefits

The principle of the FLUTTER® as a mucus clearance device is based on its ability to:

- Vibrate the airways *(which loosens mucus from the airway walls)*
- Intermittently increase endobronchial pressure *(which helps maintain the patency of the airways during exhalation so that mucus does not become trapped as it moves up the airways)*
- Accelerate expiratory airflow *(which facilitates the upward movement of mucus through the airways so that it can be more easily cleared)*

Contact:

AXCAN SCANDIPHARM INC.
22 Inverness Center Parkway
Birmingham, AL 35242 USA

Website: http://www.aptalispharma.com/pdf/Flutter_PI.pdf

**All information on this page was found on Axcan Pharma's "FLUTTER® Mucus Clearance Device: Instructions for Use" on Aptalis' website at http://www.aptalispharma.com/pdf/Flutter_PI.pdf.*

G5® Freedom Airway Clearance System

A safe, portable, self-contained, easy-to-use device for children and adults. The G5® FREEDOM™ is the only wearable airway clearance system that allows the user to assume optimal postural drainage positions. There is no claustrophobic squeeze associated with the Freedom™ System. Tighten the straps securely and let the Percussion Pods™ deliver what feels almost like a muscle massage as you simultaneously feel the energy of the Pods dislodging the mucous deep inside of your lungs.

Product Facts

- Synthetic vest with eight (8) Directional-Stroking® Percussion Pods™ positioned over major lung segments both on the front and back side of the torso
- Percussion Pods™ generate High Frequency Chest Wall Percussion (HFCWP) on specific lung segments to be treated
- Patients or therapists can select any combination of the 1-8 Pods to activate, specifying the oscillation or cycle per second range of each individual Pod
- Treatments can be programmed for up to 30 minutes with a timed safety shutoff after 35 minutes
- Generally fits pre-teens to large adults through the use of adjustable shoulder and chest straps
- Complete system includes the synthetic vest, power supply/control box, and hand-held controller
- Pediatric and bariatric models coming soon
- Patent-pending as of 3/2013

Product Benefits

- Portable, weighing in at only 10lbs
- Ultra-quiet, with no air compressor necessary for operation
- Promotes high patient compliance for usage, extremely comfortable treatments due to directional-stroking technology
- Treatment settings can be saved for easy, 1-button start-up for future treatment sessions

Contact:

FI Sales, LLC
761 North 17th Street, Unit #17
Saint Charles, IL 60174
ph: 1-630-444-1380
fax: 1-630-444-1381
sales@fisalesllc.com

Website: http://fisalesllc.com/g5_freedom

**All information on this page was found on FI Sales official website at http://fisalesllc.com/home.*

G5® GENERAL PHYSIOTHERAPY

G5® Brand Percussion Modalities are designed to treat patients of all ages who have chronic obstructive pulmonary disease or irregular breathing or coughing patterns. Their percussion modalities serve as adjuncts to therapists in performing pulmonary drainage procedures, which aid in lung ventilation and pulmonary hygiene by helping to remove accumulated secretions that cause increased airway obstruction, resistance and infection.

Flimm Fighter®

- Optimum percussor for effective, at-home, postural drainage.
- Directional-Stroking action helps loosen congestive materials and moves them into the upper airways, promoting airway clearance.

Gemini®

Provides two sized heads for more specialized therapy:

- The micro head is used on hard to reach areas, pediatrics, geriatrics, and people with sentisivity to vibration.
- The micro head provides concentrated therapy while the macro head provides therapy to larger muscle groups or areas.

Therassist®

Ideal for stress reduction, myofascial release, sports rehabilitation, deep muscle therapy, trigger point reduction, treatment of muscle spasm, pain relief by mobilizing lactic acid, and postural drainage.

Vibracare®

- Only hand-held percussor to be granted C.S.A's highest medical operational rating
- Portable, lightweight (weighs <3 lbs) hand-held device (no need for power cord)
- Comfortable soft rubber hand grip
- Used as an adjunct for postural drainage
- Available in a smaller size for Pediatrics

Neocussor® (neonatal)

- Gentle, quiet, portable model designed specifically for neonatal applications.
- Soothing, precise treatment to help loosen, and help mobilize secretion build-up in neonates.

Contact:

FI Sales, LLC
761 North 17th Street, Unit #17
Saint Charles, IL 60174
ph: 1-630-444-1380
fax: 1-630-444-1381
sales@fisalesllc.com

Website: http://fisalesllc.com/g5_freedom

**All information on this page can be found on G5's official website at www.g5.com.*

inCOURAGE® SYSTEM

inCourage® Airway Clearance Therapy

Helps loosen, thin and move mucus from throughout the lungs making breathing easier. This High Frequency Chest Compression (HFCC), or vest therapy, uses a unique triangle waveform pulse that results in more effective airway clearance therapy.

Product Facts

Consists of an inflatable jacket, two interconnecting hoses and a pulsating therapy unit (PTU). The PTU produces an air pulse that creates compressions to the chest that help loosen, thin and mobilize mucus. These pulse waves create the impact of high frequency chest compression (HFCC) to help mobilize lung secretions. The inCourage System's unique triangle wave pulses produce peak pressures for shorter durations – in contrast to sine wave technology used in other vest therapy systems.

Product Benefits

Easy to use and comes programmed with easy-to-follow instructions for three one-button-start sessions:

- A Quick Start session automatically cycles through effective therapeutic pulse frequencies.
- Auto Pause adds a break every five minutes during a QuickStart session.
- The Multi-Step feature lets you program and save individualized therapy sessions.

Other benefits include:

- *QuickFit Sizing* helps provide a repeatable fit for more consistent and effective therapy.
- *Largest Number of Jacket Sizes* available to fit 16 to 60" chest circumferences. Machine washable with no disassembly required.
- *Compact* , portable PTU design with custom travel case.
- *Locking Hose Connectors* for a simple, secure fit and consistent pulse pressure.
- *Designed for Comfort* which can lead to better adherence and better health.
- *In-home Personal Training*

Reimbursement

Coverage criteria and requested documentation differ depending on each patient's medical condition and insurance plan. High frequency chest compression (HFCC)/high frequency chest wall oscillation (HFCWO) therapy is a widely accepted therapy approved for payment by over 900 commercial insurance plans and nearly 250 government programs. The inCourage System's Customer Care, Clinical and Reimbursement Departments are ready to assist throughout the process by working efficiently and confidentially with your doctor and their team, your health insurance plan and you.

Contact:

RespirTech
2896 Centre Pointe Drive
St. Paul, MN 55113
Toll Free: 800-793-1261
Main Office: 651-379-8999
Fax: 651-379-8998

Website: www.respirtech.com

**All information* on this page was found on RespirTech's official website at *http://www.respirtech.com/incourage-airway-clearance-therapy*

IPV® IMPULSATOR®

IPV® Impulsator® for Home Care: *The Percussionaire Impulsator® (IPV®)*

A totally self contained PulmonaryTherapy System allowing COPD patients to continue daily professional quality, hospital administered IPV® therapy, "at home". The IPV® Impulsator® was designed to allow pulmonary patients of all ages with Cystic Fibrosis, Bronchitis, Asthma, Bronchiectasis, Pulmonary Emphysema and other pulmonary diseases to maintain daily hospital quality IPV® treatment schedules at home.

Product Facts

IPV® is a unique, long proven, total clinical cardiopulmonary recruitment and stabilization method and not just a method of treating the (shortness of breath) symptoms which are caused by the underlying pulmonary disease.

While IPV® is directed toward the long term preservation of the Pulmonary Blood supply to the Bronchioles, as well as the Alveoli they ventilate, it serves toward keeping the Pulmonary airways free of retained endobronchial secretions reducing the work of normal breathing.

Product Benefits

- Provides in-home set-up by a licensed Respiratory Therapist
- A video showing all applications
- A 30/60/90 day patient assessment
- Tracking for patient compliance
- A Patient Care Coordinator
- Online instructional videos at http://www.ipvhome.com/videos.asp

Reimbursement

Percussionaire® will compile and submit all documents/follow through with any issues regarding insurance. They accept patients with a qualifying diagnosis for reimbursement. Insurance companies nationwide reimburse for the Impulsator®. Some patients will pay privately for this device. At this time they are not able to accept Medicare/Medicaid.

Contact:

General Coordinator Home Care Services
Valarie Zimmerman
Phone: 208-263-2549 Ext 161
homecare@percussionaire.com

Website: http://www.ipvhome.com/impulsator.asp

**All information on this page was found on Percussionaire® Corporation's website at http://www.percussionaire.com/default.asp.*

AIRWAY CLEARANCE TECHNIQUES (ACT)

Information provided by the Cystic Fibrosis Foundation

Coughing

Coughing is the most basic ACT. It is a reflex. It clears mucus with high-speed airflow. But sometimes mucus cannot be cleared just with a lot of coughing. Coughing a lot can make you feel more short of breath and worse, not better.

Huffing

Huffing is a type of cough. It also involves taking a breath in and actively exhaling. It is more like "huffing" onto a mirror or window to steam it up. It is not as forceful as a cough but can work better and be less tiring.

Chest Physical Therapy (CPT) and Postural Drainage & Percussion (PD&P)

Chest Physical Therapy (CPT or Chest PT) or Postural Drainage & Percussion (PD&P) is an ACT. With postural drainage, the person gets in varied positions (postures) that drain mucus from different lung parts.

Gravity pulls mucus from small to large airways where it can be coughed up. With chest percussion the chest is clapped and vibrated to dislodge and move mucus. This is done in varied positions to drain all lung parts.

Active Cycle of Breathing Technique (ACBT)

Active Cycle of Breathing Technique (ACBT) involves a set of breathing techniques. It can be changed to meet each person's needs. It gets air behind mucus, lowers airway spasm and clears mucus. It includes:

- *Breathing control* – normal, gentle breathing with the lower chest while relaxing the upper chest and shoulders.
- *Thoracic expansion exercises* – deep breaths in. Some use a three-second breath-hold to get more air behind the mucus. This may be done with chest clapping or vibrating, followed by breathing control.
- *Forced expiration technique* – huffs of varied lengths with breathing control.

Autogenic Drainage (AD)

Autogenic Drainage (AD) means "self-drainage." It uses varied airflows to move mucus. It aims to reach very high airflows in different lung parts. This moves mucus from small to large airways. AD has three parts:

- Dislodging mucus
- Collecting mucus
- Clearing mucus

The person inhales to different levels and then adjusts how they breathe out to heighten airflow and move mucus. At first, AD takes hard work and practice. It is best for people over 8 years old.

To learn more, read "An Introduction to Postural Drainage and Percussion" which can be found at http://www.cff.org/UploadedFiles/treatments/Therapies/Respiratory/PosturalDrainage/An-Introduction-to-Postural-Drainage-and-Pecussion-03-2012.pdf

PARI PEP™ S

Product Facts

Positive Expiratory Pressure (PEP) device offers both traditional PEP therapy and combination PEP/Nebulizer therapy.

Positive Expiratory Pressure (PEP) is a type of therapy that creates resistance pressure during exhalation. PEP is used for airway stabilization and mucus clearance. PEP is recommend for patients diagnosed with Cystic Fibrosis or lung diseases with secretory problems

Product Benefits

Designed for use with the PARI LC® Plus or LC® Sprint, combination therapy provides concurrent PEP therapy with clinically proven aerosol delivery. Shorter daily treatment regimens and clinically proven aerosol delivery result in an improved patient quality of life.

- Eight resistance setting covers a large expiratory flow range that offers pressure of 10-20cm of H_2O
- Dishwasher safe and boilable

Contact

PARI Respiratory Equipment, Inc.
2412 PARI Way
Midlothian, VA 23112
Tel: 1.800.FAST.NEB (327.8632)
Fax: 1.800.727.4112
Email: productinfo@PARI.com

Website: http://www.pari.com/products/accessories

**All information on this page was found on PARI's official website at http://www.pari.com/products/accessories_other/product/detail/info/pari_pep_s.html*

The RC-Cornet®

The RC-Cornet, by Curaplex, is a reusable single-patient device that provides oscillatory positive expiratory pressure (OPEP) therapy for the detachment and removal of pulmonary secretions.

Product Facts

Through variable pressure settings and optional aerosolized medication delivery, patients realize maximum efficacy specific to their unique clinical needs.

The RC-Cornet uses the patient's full expired air volume to produce pressure and oscillatory vibrations. The success of OPEP therapy depends on these vibrations, especially for patients with a low expiratory volume.

Product Benefits

- *Dual therapy* - Simultaneous, efficient and effective administration of aerosolized medications while patients receive bronchial hygiene therapy.
- *Patient comfort* - Non-gravity dependent technology allows patient to administer therapy in various positions.
- *Single device* - A single device with multiple applications reduces multiple stock numbers and overall cost.
- *Reusable* - The mouthpiece and valve hose can be easily removed from the tube for cleaning in the dishwasher, an autoclave or disinfectant solution (see instructions for use for complete details).

Contact:

Curaplex®
5000 Tuttle Crossing Blvd
Dublin, OH 43016
Phone: (855) 287-2759

Website: http://www.curaplex.com/rc_cornet.asp

**All information on this page was found on Curaplex's official website at http://www.curaplex.com/.*

SmartVest® SYSTEM

SmartVest ® Airway Clearance System

A patented medical device that uses High Frequency Chest Wall Oscillation (HFCWO) technology to improve airway clearance and remove excess mucus from the lungs. The SmartVest® is often used as an alternative to manual Chest Physiotherapy (CPT) to provide an effective and comfortable airway clearance experience.

Product Facts

The SmartVest® works by gently and rapidly compressing and releasing the chest wall, creating a special airflow within the airway. The air pulse actions of the SmartVest® produce pressures that are similar to a natural cough and move mucus from the small airways to the larger airways, where it can be coughed out. The SmartVest® is available only by a physician's prescription.

Product Benefits

The SmartVest® system is portable, programmable, and user-friendly.

The SmartVest® Airway Clearance System comes with:

- A programmable air pulse generator
- Vest or wrap garment
- Single-hose
- Instruction manual
- Training DVD
- An in-home trainer *(who will ensure that you or your caregiver is comfortable with operating the System)*

In addition to the physical device, the SmartVest® comes with the full backing and support of Electromed, Inc., maker of the SmartVest®. Services provided include:

- In-home training by a licensed medical professional
- Exceptional customer service
- Toll-free support HELPLINE (888-966-2525)
- Insurance reimbursement assistance
- No-risk trial period
- Individual life time warranty

Reimbursement

Medicare, many insurance plans, numerous state medical assistance programs, and the Department of Veterans Affairs cover the SmartVest® for most individuals. SmartVest® Reimbursement Specialists will work closely with you, your medical team, and your insurance provider to find the solution that works best for you.

Contact:

Corporate Headquarters
500 Sixth Avenue NW
New Prague, MN 56071
Phone: 800-462-1045 or 952-758-9299
Fax: 866-758-5077 or 952-758-5077

Website: www.Electromed.com & www.SmartVest.com

**All information on this page was found on SmartVest's official website at http://www.smartvest.com/.*

THE VEST®

The Vest® Airway Clearance System

Designed to assist patients in the mobilization of retained secretions that, if not removed, may lead to increased rates of respiratory infection, hospitalization, and reduced lung function.

The Vest® Airway Clearance System, Model 105, represents 5th generation technology from the innovators of High Frequency Chest Wall Oscillation or HFCWO. This therapy utilizes a device that generates increased airflow velocities that create cough-like shear forces and decreases secretion viscosity.

Product Facts

- High-Frequency Chest Wall Oscillation (HFCWO), creates mini-coughs that dislodge mucus from the bronchial walls, increase mobilization, and move it along toward central airways.
- Works to thin thick secretions, making them easier to clear. Once the mucus has moved from the smaller to larger airways, it can be easily removed by coughing or suctioning.
- More than 80 studies in more than 60 facilities – spanning over 20 years of research – demonstrate the efficacy and safety of HFCWO for a variety of patients.

Product Benefits

- Unlike manual chest percussion therapy (CPT), The Vest® System treatment does not require special positioning or breathing techniques.
- The technology is technique-independent because patient or caregiver factors do not compromise its effectiveness.
- A typical treatment takes 15-20 minutes.
- Proven effective.

Reimbursement

- Prescribed for more than 97,000 people with airway clearance needs.
- Prescribed by more than 17,000 physicians nationwide.
- Approved for payment by more than 900 commercial insurance companies and 250 government-funded payers.

Contact:

1020 West County Road F
St. Paul, MN 55126
Phone: 800-426-4224 or 651-490-1468
Fax: 877-368-5081 or 651-234-1209

Website: www.thevest.com/

**All information on this page was found on The Vest's official website at http://www.thevest.com/ .*

TheraPEP® Positive Expiratory Pressure Therapy System

The easy-to-use system for mobilizing secretions in patients with Cystic Fibrosis (CF), lung diseases with secretory problems and to prevent or reverse atelectasis, as well as patients recovering from surgery. Unlike labor-intensive, time-consuming chest physiotherapy (CPT), Positive Expiratory Pressure (PEP) Therapy with TheraPEP® PEP Therapy System can be self-administered by the patient in any setting, in less than half the time required for CPT.

Product Facts

- Improves secretion clearance, facilitates opening of airways, and effectively reverses atelectasis.
- May reduce need for postural drainage.
- Can be performed in less than half the time of a conventional Chest Percussion Therpay session.[3]
- Helps patient maintain effective continuum of care outside the hospital.
- Clinicians can do two treatments in the time of one.

3. Mahlmeister MJ, Fink JB, Hoffman GL, Fifer LF. "Positive-expiratory-pressure mask therapy: Theoretical and Practical Considerations and a Review of the Literature", Respiratory Care, 1991;36:1218-1230.

Product Benefits

- Can accommodate virtually any patient's lung capacity.
- Resists breakage, unlike fragile, costly manometers.
- Provides immediate, visual 360º feedback of prescribed pressure.
- May be used with a mask or mouthpiece, or nebulizer.
- Allows inhalation and exhalation without removing from mouth.

Contact:

Smiths Medical ASD, Inc.
160 Weymouth Street
Rockland, MA 02370 (USA)
Tel: (800) 848-1757
Fax: (800) 621-2950

Website: www.smiths-medical.com/respiratorycare

**All information on this page was found on Smith-Medical's official website at http://www.smiths-medical.com/*

An Introduction to Postural Drainage & Percussion

Postural Drainage and Percussion (PD & P), also known as chest physical therapy (CPT), is a way to help people with cystic fibrosis (CF) breathe with less difficulty and stay healthy. PD & P uses gravity and percussion to loosen the thick, sticky mucus in the lungs so it can be removed by coughing. Unclogging the airways is key to keeping lungs healthy.

PD & P is easy to do using the techniques described here. For the child with CF, PD & P can be done by physical therapists (PT), respiratory therapists (RT), nurses, parents, siblings and even friends.

People with CF sometimes use other types of treatments, such as inhaled bronchodilators and antibiotics to keep their lungs healthy. If ordered, bronchodilators should be taken **before** PD & P to open the airways, and inhaled antibiotics should be taken **after** PD & P so that the medicine gets to the infection better. Your care center doctor or therapist will help you figure out a routine that will work best for you or your child.

KNOW YOUR LUNGS

Learning more about the respiratory system and its relationship to other organs in the body can help you to understand why PD & P treatments are effective.

Getting Rid of Mucus

The goal of PD & P is to clear mucus from each of the five lobes of the lungs by moving mucus into the larger airways so that it can be coughed out. The right lung is composed of three lobes: the upper lobe, the middle lobe and the lower lobe. The left lung is made up of only two lobes: the upper lobe and the lower lobe.

The lobes are divided into smaller sections called segments. The upper lobes on the left and right sides are each made up of three segments: **top (apical)**, **back (posterior)** and **front (anterior)**.

The lungs are made up of a network of air tubes, air sacs and blood vessels. These sacs allow for the exchange of oxygen and carbon dioxide between the blood and air. It is these segments that are being drained. Note the position of each lung segment in Figure 1 below.

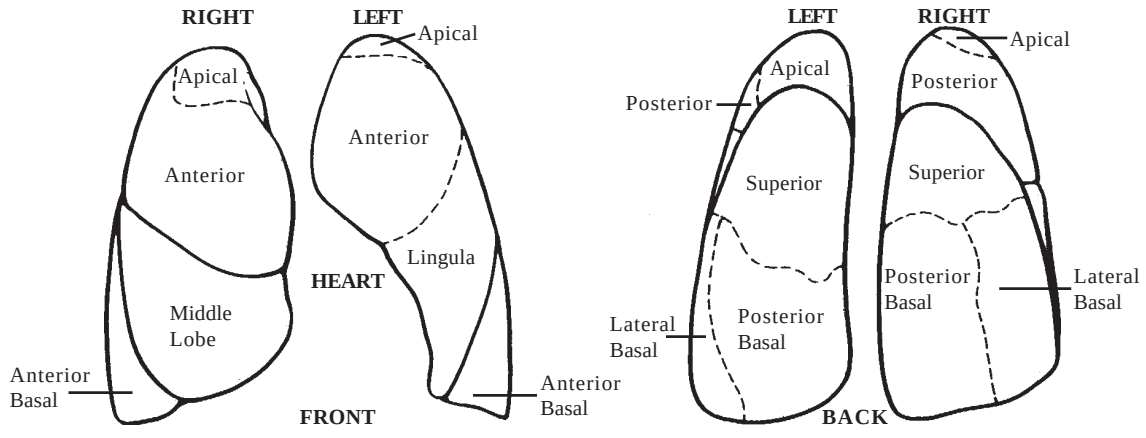


Figure 1: External Anatomy of the Lung

*Words that appear in bold italic are defined on page 3.

National Office
6931 Arlington Road Bethesda, Maryland 20814
(301) 951-4422 (800) FIGHT CF www.cff.org

PERFORMING PD & P

The performance of PD & P involves a combination of techniques including: multiple positions to drain the lungs, percussion, vibration, deep breathing and coughing.

Once the person is in one of the positions, the caregiver does percussion on the chest wall. This is usually given for a period of three to five minutes and sometimes followed by vibration over the same area for approximately 15 seconds (or during five ***exhalations***). The person is then encouraged to cough or huff forcefully to get the mucus out of the lungs.

Description of PD & P Techniques

Postural drainage uses gravity to help move mucus from the lungs up to the throat. The person lies or sits in various positions so that the part of the lung to be drained is as high as possible. The part of the lung is then drained using percussion, vibration and gravity. For a complete description of these positions, see diagrams on pages 4 through 7. Your CF care team may tailor these positions to yours or your child's needs.

Percussion or clapping by the caregiver on the chest wall over the part of the lung to be drained helps move the mucus into the larger airways. The hand is cupped as if to hold water but with the palm facing down as in Figure 2. The cupped hand curves to the chest wall and traps a cushion of air to soften the clapping.

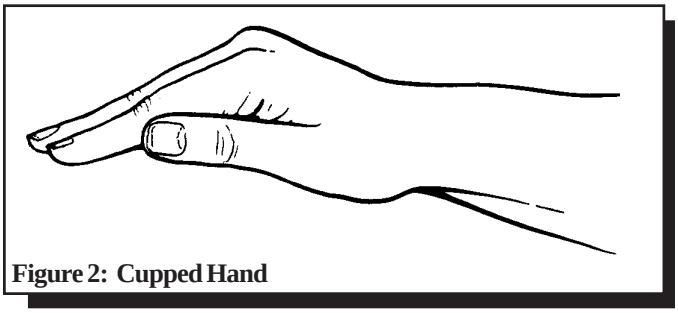


Figure 2: Cupped Hand

Percussion is done forcefully and with a steady beat. It should not be painful or sting if the hand is cupped properly. Each percussion also should have a hollow sound. Most of the movement is in the wrist with the arm relaxed, making percussion less tiring to do.

Special attention must be taken to not clap over the spine, breastbone, stomach and lower ribs or back to prevent injury to the spleen on the left, the liver on the right and the kidneys in the lower back.

Different devices may be used in place of the traditional cupped palm method for percussion. Ask your doctor or therapist for advice.

Vibration gently shakes the mucus into the larger airways. The caregiver places a hand firmly on the chest wall over the part of the lung being drained and tenses the muscles of the arm and shoulder to create a fine shaking motion. Then, the caregiver applies a light pressure over the area being vibrated. (The caregiver also may place one hand over the other, then press the top and bottom hand into each other to vibrate.) Vibration is done with the flattened hand, not the cupped hand, as in Figure 3. Exhalation should be as slow and as complete as possible.

Deep breathing moves the loosened mucus and may lead to coughing. Breathing with the ***diaphragm***, belly breathing or lower chest breathing is used to help the person take deeper breaths and get the air into the lower lungs. The belly moves outward when the person breathes in and sinks in when he or she breathes out.

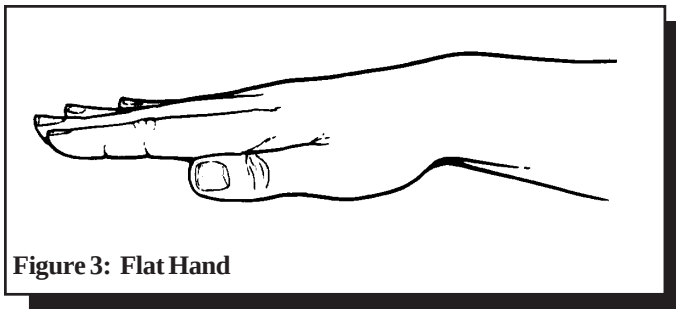


Figure 3: Flat Hand

Coughing is key in clearing the airways of mucus. A forced but not strained exhalation, following a deep ***inhalation***, may help a person cough. The mucus can then be coughed out.

Huffing

Huffing is a type of cough. It also involves taking a breath in and actively exhaling. It is more like "huffing" onto a mirror or window to steam it up. It is not as forceful as a cough but can work better and be less tiring.

Timing of PD&P

Generally, each treatment session can last for 20 to 40 minutes. PD & P is best done before meals or one and a half to two hours after eating to decrease the chance of vomiting. Early morning and bedtimes usually are recommended. The length of PD & P and the number of times of day it is done may need to be increased if the person is more congested or getting sick. Your CF doctor or therapist will help you know what positions, how often and how long PD & P should be done.

ENHANCING PD & P FOR THE PERSON AND CAREGIVER

Both the person with CF and the caregiver should be comfortable during PD & P. Before starting, the person should remove tight clothing, jewelry, buttons and zippers around the neck, chest and waist. Light, soft clothing, such as a T-shirt, may be worn. **Do not do PD & P on bare skin.** The caregiver should remove rings and other bulky jewelry such as watches or bracelets. A supply of tissues or a place to cough out the mucus should be nearby.

Doing PD & P Comfortably and Carefully

The caregiver should not lean forward when doing percussion, but should remain in an upright position to protect his or her back. The table on which the person with CF lies should be at a comfortable height for the caregiver.

Purchasing Equipment

Equipment such as drainage tables, electrical and non-electrical palm percussors and vibrators may be helpful. These can be purchased from medical equipment stores. Older children and adults may find percussors useful when doing their own PD & P.

Talk to your doctor or therapist at your CF care center about equipment for PD & P.

Pillows, sofa cushions, bundles of newspapers under pillows for support, cribs with adjustable mattress heights/tilts, foam wedges and bean bag chairs work for many families. Infants can be positioned with or without pillows in the caregiver's lap.

Making PD & P More Enjoyable

To enhance the quality of the time you spend doing PD & P, do one of the following:

- Schedule PD & P around a favorite TV show.
- Play favorite songs or recorded stories.
- Spend time playing, talking or singing before, during and after PD & P.
- For kids, encourage blowing or coughing games during PD & P, such as blowing pinwheels or coughing the deepest cough.
- Ask willing and capable relatives, friends, brothers and sisters to do PD & P. This can provide a welcome break from the daily routine.
- Minimize interruptions.

Finding ways that make PD & P more enjoyable can help you keep a regular routine and get maximum health benefits.

Glossary

Diaphragm: The main breathing muscle – a dome-shaped muscle between the chest and abdomen. People with CF may learn to use the diaphragm to cough better or make breathing easier.

Exhalation(s): Breathing out; the flow of air out of the lungs with each breath.

Inhalation: Breathing in; the flow of air into the lungs.

INSTRUCTIONS FOR POSTURAL DRAINAGE POSITIONS

The following diagrams describe the positions for PD & P. In the diagrams, shaded areas show where the chest should be percussed or clapped.

Pillows may be used for added comfort. If the person tires easily, the order of the positions can be varied, but all areas of the chest should be percussed or clapped.

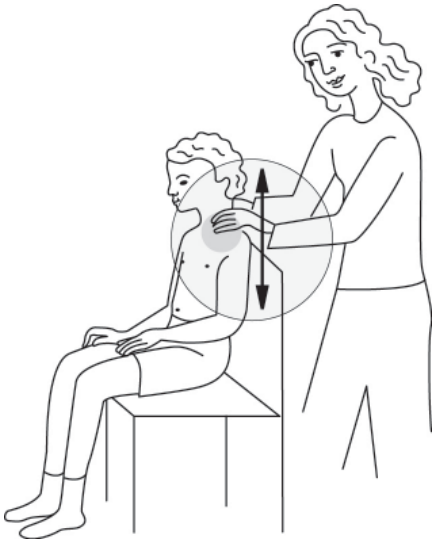
Please remember to percuss and vibrate only over the ribs. Avoid percussing and vibrating over the spine, breastbone, stomach and lower ribs or back to prevent trauma to the spleen on the left, the liver on the right and the kidneys in the lower back. Do not percuss or vibrate on bare skin.

Self-Percussion — Upper Lobes

Your child should sit upright and reach across his or her chest to clap on front of chest over the muscular area between the collarbone and the top of the shoulder blade. Repeat on the opposite side. Your child can also clap his or her own upper back if able to reach it.

Upper Front Chest — Upper Lobes

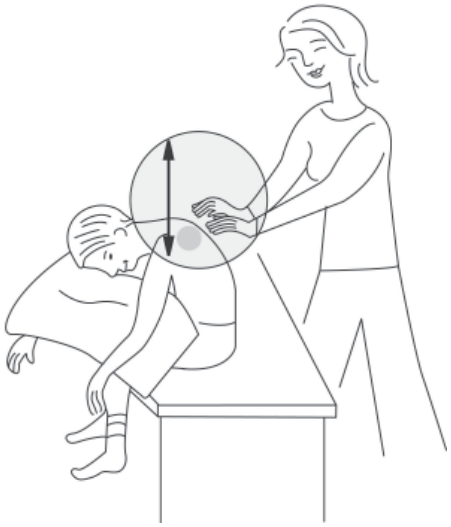
Have your child sit upright. Clap on both sides of upper front chest over the muscular area between the collarbone and the top of the shoulder blade.



* Children shown without shirts to better demonstrate the PD & P technique in illustrations. Images are from the CF Family Education Program.

Upper Back Chest — Upper Lobes

Have your child sit up and lean forward on a pillow over the back of a sofa or soft chair at a 30 degree angle. Stand or sit behind your child and clap both sides of the upper back. Take care not to clap on your child's backbone.



Upper Front Chest — Upper Lobes

Have your child lie on his or her back with arms to sides. Stand behind your child's head. Clap both sides of your child's chest between the collarbone and nipple.

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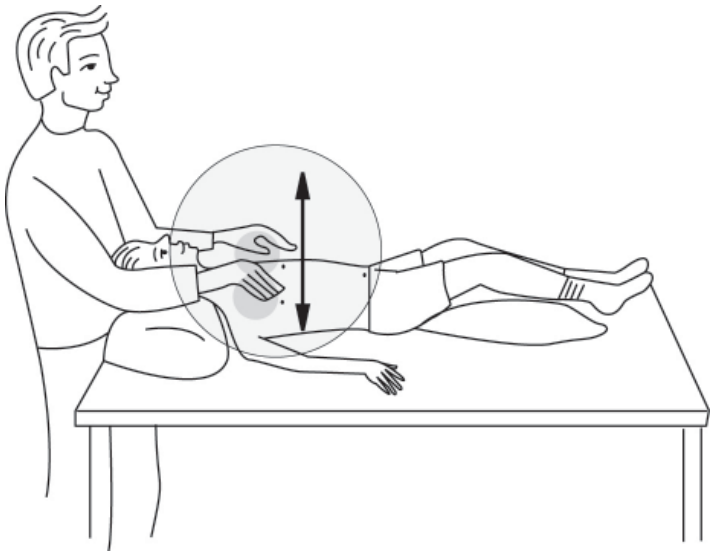
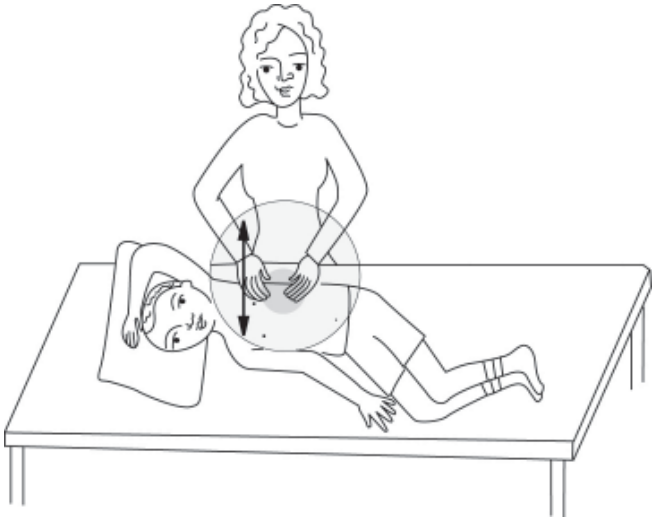


Left Side Front Chest

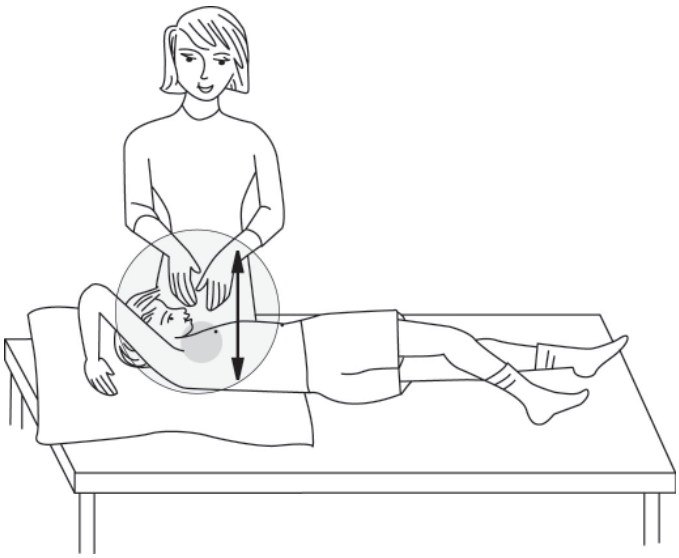
Have your child lie with left side up and raise his or her left arm over head. Clap over the lower ribs just below the nipple area on front side of left chest. Do not clap on your child's stomach.



* Children shown without shirts to better demonstrate the PD & P technique in illustrations. Images are from the CF Family Education Program.

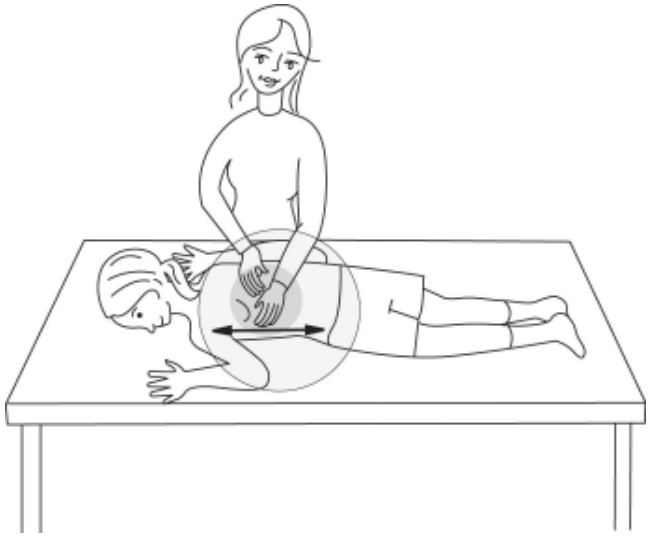
Right Side Front Chest

Have your child lie with right side up and raise right arm over head. Clap over the lower chest just below the nipple area on front side of right chest. Do not clap lower ribcage.



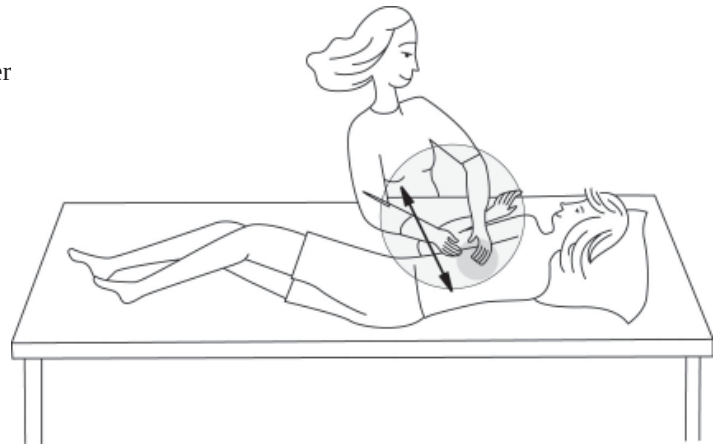
Lower Back Chest — Lower Lobes

Have your child lie on his or her stomach. Clap both sides at the bottom of chest just above the bottom edge of the ribcage. Do not clap lower ribcage or over the backbone.



Left Lower Side Back Chest — Lower Lobe

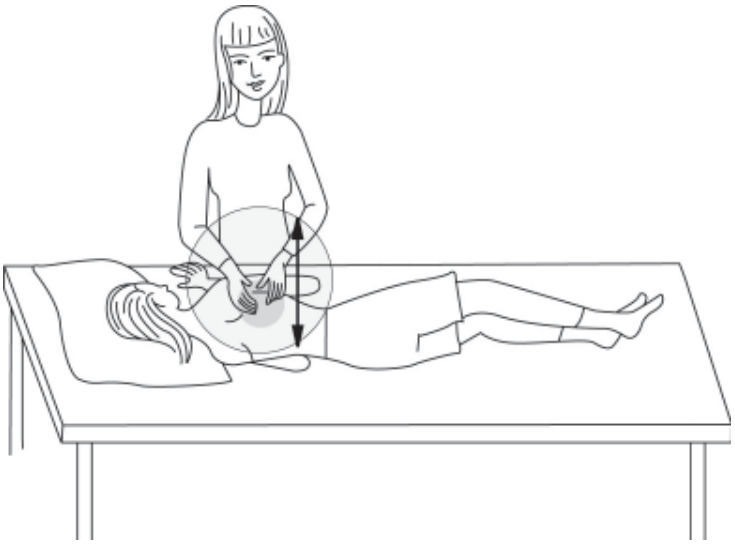
Have your child lie with left side up and roll toward you a quarter turn so you can reach your child's back. Clap on lower left side of chest just above the bottom edge of the ribcage.



* Children shown without shirts to better demonstrate the PD & P technique in illustrations. Images are from the CF Family Education Program.

Right Lower Side Back — Lower Lobe

Have your child lie right side up and roll toward you a quarter turn so you can reach your child's back. Clap on lower right side of the chest just above the bottom edge of the ribcage.



* Children shown without shirts to better demonstrate the PD & P technique in illustrations. Images are from the CF Family Education Program.

NON-PROFIT ORGANIZATIONS

A non-profit is a tax-exempt organization that serves the public interest. In general, the purpose of this type of organization must be charitable, educational, scientific, religious or literary. Legally, a non-profit organization is one that does not declare a profit and instead utilizes all revenue available after normal operating expenses in service to the public interest.

Definition provided by: http://www.nonprofit.pro/nonprofit_organization.htm

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The Blooming Rose Foundation and Foundation Care have compiled a list of cystic fibrosis-related nonprofit organizations in the United States. It is important that you find resources specific to you and your family's needs. The mission of these organizations is to provide the CF community with education, an increased quality of life, financial assistance, and much more.

**This is not a comprehensive list of all non-profits dedicated to serving the cystic fibrosis population. We will periodically update this section for our patients and physicians. If you would like your organization to be included in one of our updates, please email your information to: help@foundcare.com*

NON-PROFIT ORGANIZATIONS

Blooming Rose Foundation

The Blooming Rose Foundation was founded in 2009 to educate and advocate for the CF community. We provide newly diagnosed families with information and connect them with critical resources that will help them cope physically, mentally, emotionally, and financially. BRF also specializes on the promotion of using exercise and proper nutrition as CF therapy. We develop and share therapy techniques and endorse diets focused on both macro and micronutrients. We advocate for alternative therapies to be widely recognized as integral for disease management. Through all of its programs, The Blooming Rose Foundation helps improve the lives of individuals and families with cystic fibrosis.
www.BloomingRoseFoundation.org

Boomer Esiason Foundation

Boomer Esiason Foundation is a dynamic partnership of leaders in the medical and business communities joining with a committed core of volunteers to heighten awareness, education, and quality of life for those affected by cystic fibrosis, while providing financial support to research aimed at finding a cure.
www.esiason.org

Claire's Place Foundation

Claire's Place Foundation, Inc. is a 501c3 non-profit organization designed to help children and families affected by Cystic Fibrosis. Claire's Place Foundation is named in honor of Claire Wineland, now a teenager, who has been living with cystic fibrosis her entire life. Claire and her parents want other families to experience the benefit from the kind of support that they received and continue to get; hence, this is the motivation for the foundation. Claire's experiences have catapulted her into a position of being a spokesperson and an inspirational model for people living with this disease. She has documented and created videos on how to enjoy life with Cystic Fibrosis and live life to the fullest. Claire's Place Foundation is a way for Claire to give back and make meaning of what she has had to go through; the foundation is her way to enrich the human experience with hope, strength and joy.
http://clairesplacefoundation.org/

Cystic Fibrosis Foundation

The Cystic Fibrosis Foundation (CFF) is a nonprofit donor-supported organization dedicated to attacking cystic fibrosis from every angle. Our focus is to support the development of new drugs to fight the disease, improve the quality of life for those with CF, and ultimately to find a cure.
www.cff.org

Cystic Fibrosis Lifestyle Foundation

The Cystic Fibrosis Lifestyle Foundation (CFLF) is about guiding the choices made to live successfully with CF. Through recreation grants and educational programs CFLF assists people living with CF to thrive, not just survive. By inspiring healthy and active lifestyles through fitness, exercise, and outdoor recreation activities the CFLF educates people living with Cystic Fibrosis about the critical psychological, social and emotional connections between their lifestyle and their health. The Foundation works to achieve its mission through developing and providing opportunities for people with CF to become aware of a lifestyle that achieves health, as opposed to avoiding illness.
www.cflf.org

NON-PROFIT ORGANIZATIONS

Cystic Fibrosis Research Inc

Cystic Fibrosis Research, Inc. (CFRI) exists to fund research, to provide educational and personal support, and to spread awareness of cystic fibrosis, a life-threatening genetic disease.
www.cfri.org

Cystic Fibrosis Scholarship Foundation

The Cystic Fibrosis Scholarship Foundation (CFSF) is a non-profit organization devoted to providing an opportunity for young adults with CF to further their education at a college or vocational school. CFSF scholarships are awarded based on educational achievement, leadership, and financial need as submitted by the student in the scholarship application form.
www.cfscholarship.org

Disability Advocates For Cystic Fibrosis

Disability Advocates for Cystic Fibrosis is a non-profit that aims to provide free application and filing services for social security disability claims for those living with cystic fibrosis.
www.dafcf.org

Elizabeth Nash Foundation

The Elizabeth Nash Foundation was established in 2003 by her family to honor and perpetuate Liz's lifelong example of giving and to continue her fight against cystic fibrosis. The foundation is a donor supported 501(c)3 non-profit, public benefit charity operated by a family board. There are no administrative costs or salaries. Donations are tax deductible and go 100% to programs and benefits for CF individuals.
www.elizabethnashfoundation.org

Help One Love One

Help One Love One is an organization that provides funding to adults with cystic fibrosis, primarily to aid with their nutritional needs. They provide other assistance when financially possible.
www.helponeloveone.org

Liv for a Cure

Liv for a Cure was founded to help the 30,000 children and young adults in the United States afflicted with cystic fibrosis (CF). This foundation is working with the Cystic Fibrosis Center at Children's Memorial Hospital to provide funding for research in hope of finding a cure and to provide a better quality of life while they fight this disease.
www.livforacure.org

Mauli Ola Foundation

The Mauli Ola Foundation began as a group of surfers who banded together to introduce surfing as a natural treatment to people with cystic fibrosis. Since 2007, Mauli Ola has taken nearly 1,300 CF patients surfing at nearly 100 Surf Experience Days and has now expanded its reach with hospital visits and other activities that touch the lives of kids with cancer and a variety of other health challenges.
www.mauliola.org

NON-PROFIT ORGANIZATIONS

Reaching Out Foundation

Reaching Out Foundation is sensitive to the needs of patients and families with Cystic Fibrosis and provides financial and educational resources to assist them.
www.reachingoutfoundation.org

Rock CF Foundation

Rock CF Foundation is a US-based non-profit organization that uses the arts, entertainment, fashion, and fitness to increase awareness and raise funds for cystic fibrosis. Founded and led by Emily Schaller, the Rock CF Foundation is dedicated to increasing the quality of life for people with Cystic Fibrosis.
www.letsrockcf.org

The United States Adult Cystic Fibrosis Association Inc

The United States Adult Cystic Fibrosis Association Inc (USACFA) is a non-profit, 501(c)(3) organization, run by 12 volunteer Directors who all have CF. Since 1990, USACFA has published a quarterly newsletter, *CF Roundtable*, which offers hope, support, and news in the world of cystic fibrosis. Now you can get even more through their newly updated website. So regardless of whether you have CF, care for someone with it, or simply know a person who has it, you'll find helpful and encouraging information here.
www.cfroundtable.com

RESOURCE MATERIALS

The cystic fibrosis patient population is small and so is the amount of resources available. Therefore, finding information about the disease can be frustrating and time consuming.

So where do you turn to for answers?

The following resources provide a variety of support, advocacy and educational information for cystic fibrosis patients and their families. For those who are living with CF, these pages may provide valuable resources to help them manage their disease.

**This directory is not all encompassing, nor is it an endorsement of these organizations and the programs they provide.*

BOOKS

EDUCATIONAL AND HOW TO

Educational Booklets — Foundation Care Pharmacy

A Parents Reference: Caring for an Infant/Child with Cystic Fibrosis
A booklet for parents of children recently diagnosed with CF to help them plan for the future.

A Teen's Guide: Managing Your Life with Cystic Fibrosis
Designed to help teens balance their schoolwork and social life with their disease.

The Amazing Story of Huxi: A Panda with Cystic Fibrosis
A coloring book designed to be a fun and educational tool to teach children (with and without CF) about cystic fibrosis.

**To request a free copy, please email help@foundcare.com.*

Living with CF Series — CysticLife

Life After the Diagnosis
This guide helps newly diagnosed parents through the months following their child's diagnosis.

Caring for Your Infant
This booklet helps parents navigate the first year of their child's life.

Caring for Your Toddler and Preschooler
This booklet guides parents through the early years of their child's life.

The Elementary School Years
This booklet discusses the process of transition, school issues, health guidelines, and advice from other parents for school-age children with CF.

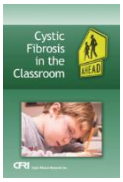
Staying Connected as a Couple
This booklet teaches parents how to stay connected as a couple while parenting a child or children with health issues.

**To download a free copy, please visit: http://www.cysticlife.org/cystic-fibrosis-reading-materials.php*

Educational Publications — Cystic Fibrosis Research Inc. (CFRI)

Cystic Fibrosis Website Guide
This guide contains a listing of website addresses for various resources, such as cystic fibrosis support organizations, patient assistance programs, and basic cystic fibrosis information.

BOOKS



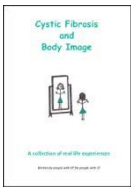
Cystic Fibrosis in the Classroom

CFRI is pleased to announce that Cystic Fibrosis in the Classroom publications are available to the CF community in English and Spanish. This is an important resource for teachers, nurses, school administrators, and everyone who has a child attending school.

**Download a free PDF copy at www.cfri.org/educate.shtml*

Cystic Fibrosis and Body Image

Written by people with CF for people with CF; Presented by CF Trust



A Collection of Real Life Experiences

We know that it is not only physical health that is important because what is the benefit of good health when we do not feel comfortable with our own image? It is normal for people to struggle with their body image at times, but CF can create some extra challenges for us to overcome. The booklet's main aim is to share experiences. You may find some of the content doesn't apply to you, but hopefully there is something for everyone.

Parenting Children With Health Issues

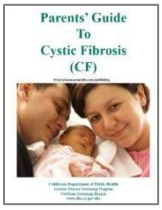
Foster W. Cline, MD and Lisa C. Greene

A ground-breaking new program to help parents and professionals address the behavioral and emotional issues associated with raising children with chronic illness, medical conditions, and special healthcare needs.

www.ParentingChildrenWithHealthIssues.com

Parents' Guide To Cystic Fibrosis

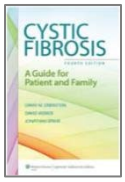
By California Department of Public Healthy



Your health care provider may have told you your baby has cystic fibrosis (CF). Babies can look healthy at birth and still have this disorder, but babies, who are not treated, often have serious and permanent health problems. With early and ongoing care, your baby should develop normally, both physically and mentally. This booklet was written to help parents learn more about this disorder. Use this booklet to learn how to care for your child. This is the ideal book to use if someone in your family is coping with cystic fibrosis. This is an inspirational booklet for families all over.

Cystic Fibrosis

By David Orenstein, Jonathan E. Spahr MD, Daniel J. Weiner MD



A Guide for Patient and Family

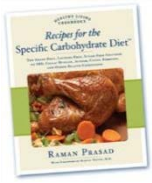
This one-of-a-kind guide offers easy-to-understand explanations, advice, and management options for patients or parents of patients with cystic fibrosis. The book explains the disease process, outlines the fundamentals of diagnosing and screening, and addresses the challenges of treatment for those living with CF.

BOOKS

Taking Cystic Fibrosis to School — By Cynthia S. Henry and Tom Dineen

In Taking Cystic Fibrosis to School, Jessie explains to her classmates that even though she has cystic fibrosis, she can still attend school.

Recipes for the Specific Carbohydrate Diet — By Raman Prasad



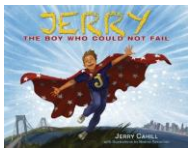
The Grain-Free, Lactose-Free, Sugar-Free Solution to IBD, Celiac Disease, Autism, Cystic Fibrosis, and Other Health Conditions (Healthy Living Cookbooks)
For those suffering from gastrointestinal illnesses, this book offers a method for easing symptoms and pain, and ultimately regaining health.

What's Up With Beth? — Medikidz

Beth doesn't understand why she always seems to have a lung infection, and is upset that being unwell is taking over her life – most especially when she has to miss her very best friend's birthday party. Luckily the Medikidz are on the case and whisk Beth on a trip to Mediland in order to teach her all the facts about Cystic Fibrosis - what causes the condition and how she can cope with it so that she can get on with what she likes. Join the Medikidz on an edu-taining trip to the lungs and pancreas, and find out all the facts you never knew about mucus!

**To order this booklet, please visit www.medikidz.com*

Jerry, the Boy Who Could Not Fail — By Jerry Cahill



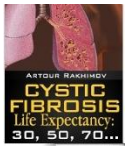
This children's book is about a little boy with CF who does not let his disease slow him down.

**Order this book by emailing jerrypv17@aol.com or jcahill@esiason.org.*

Now That I Have CF — Provided By Solvay Pharmaceuticals

Information for Men and Women Diagnosed as Adults
The intent of the book is to provide an overview of what is known about adult-diagnosis in CF; guidance in performing self-care and maintaining optimum health; and information to assist those affected understand and cope with the medical, physical, and emotional challenges of this disease.

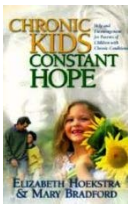
Cystic Fibrosis Life Expectancy: 30, 50, 70... — By Artour Rakhimov



Cystic fibrosis is a lifestyle disease. Very few Westerners are aware that there are many Russian people with CF (cystic fibrosis) who are over 50 and even 60 years old due to their adherence to one medical therapy that was developed and practiced by over 150 Soviet and

Russian doctors. Since 1960s, these MDs have applied the Buteyko breathing therapy to increase body O2 levels, and these doctors claim that people with CF can have at least normal (or average) life expectancy if they maintain high (or normal) body O2 content. You will not find such information in any other cystic fibrosis books.

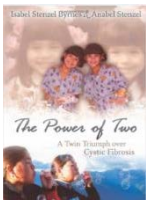
Chronic Kids, Constant Hope — By Elizabeth M. Hoekstra and Mary Bradford



Help and Encouragement for Parents of Children with Chronic Conditions
With the heart and understanding of moms who are living it themselves, Elizabeth Hoekstra and Mary Bradford offer encouragement and help for fellow parents of "chronic kids." Hoekstra and Bradford address specific issues such as dealing with emotions, what to do when friends say insensitive things, praying effectively, finding good medical care, and navigating the insurance maze. Through their honesty, the experiences of other parents, and your own chronic kid, you will discover how to recognize and absorb God's grace and hope as you live out His plan for your lives.

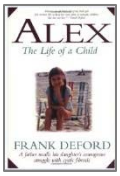
BIOGRAPHIES & AUTOBIOGRAPHIES

The Power of Two — By Isabel Stenzel Byrnes and Anabel Stenzel



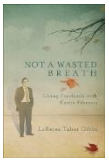
Born in 1972 in California to Japanese and German immigrant parents, Ana and Isa are identical twins who recount their lifelong struggle to pursue normal lives with cystic fibrosis while grappling with the realization that they will die young. This coming-of-age story reveals their tumultuous battle against their bodies, their desire for independent identities and their gradual acceptance of being loveable despite being physically different.

Alex: The Life of a Child — By Frank Deford



Alexandra Deford, a precious and precocious girl, was just eight years old when she died in 1980 following a battle against the debilitating effects of cystic fibrosis, the number-one genetic killer of children. Her poignant and uplifting story touched the hearts of millions when it was first published and then made into a memorable television movie. A new introduction contains information on the latest cystic fibrosis research, and a touching postcript reveals how the Deford family came to terms with the loss of Alex.

Not a Wasted Breath — By LaRecea Tabor Gibbs



Not a Wasted Breath is not just a story about living with a fatal disease or waiting for a transplant. That was only a part of Todd's life. He never allowed his illness to rule his life, even in the face of over eighty hospitalizations. This is truly a story about how others perceived Todd, how they were affected by his presence in their lives, and how Todd viewed himself and his existence. In a poignant compilation of thoughts, memories, articles, and journal

entries, LaRecea Gibbs, Todd's mother, creates a touching tableau of a life well spent that will inspire anyone to overcome personal obstacles through faith, determination, courage, and most of all, humor.

Sixty-Five Roses — By Heather Summerhayes Cariou, Foreword by Celine Dion

A Sister's Memoir
A loving, funny and profoundly moving literary memoir. The redemptive story of two sisters growing up in the shadow of a fatal illness, and a family fighting for a child's life.

The Spirit of Lo — By Terry Detrich

An Ordinary Family's Extraordinary Journey
An ordinary family is faced with an extraordinary challenge – a child with cystic fibrosis. This is their story, rich and moving, as they laugh and cry and learn and grow. Their love, faith and commitment to each other carry them through battles with depression, anger, despair, and the ravages of the disease as they join a race with death for a cure.

Breathing for a Living: *A Memoir* — By Laura Rothenberg

A moving account by an extraordinary young woman who mounts a daily struggle with cystic fibrosis in an effort to lead an ordinary life. Twenty-one-year-old Laura Rothenberg has always tried to live a normal life -- even with lungs that betray her, and a sober awareness that she may not live to see her next birthday. The memoir opens with Rothenberg's decision to accept a lung transplant. From the waiting -- and all it implies to the surgery, recovery, and her new life, Rothenberg muses on mortality in journal entries and poetry. Through it all, she reveals a will and temperament that is strong and wise despite her years.

Robyn's Book: *A True Diary* — By Robyn Miller

Miller was 21 when she died last summer, after living all her life with cystic fibrosis. But in her own way, she managed to cram a lot of feelings into that short life, and this book is her legacy. Perhaps the strongest impression her story creates is how hard she fought to reach out from the prison of her illness and help others understand her. It was an isolated life, with her loneliest moments coming when a friend, suffering from the same disease, withdraws her friendship and later dies. In this diary, Miller doesn't sound like a normal teenager; she sounds much wiser. Those who discover Robyn's Book will take much away with them.

Sick Girl Speaks! — by Tiffany Christensen

Lessons and Ponderings Along the Road to Acceptance
Surprise I'm still not dead Okay, sure, I was born with an incurable genetic disease and, yes, I have faced terminal illness two times. Along the way, I've had to learn some pretty painful

lessons about how to advocate for myself and what happens if I don't. I also know how scary and disorienting illness can be-I have a lot to say about finding peace and acceptance, no matter what your diagnosis. I offer you my advice, my humor and my personal journals as a window into the often quiet world of living with illness. Whether you are a patient, family member or medical professional, chances are you will find something between these pages that you never knew. Medicine is a complicated maze.

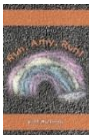
The Stones Applaud — By Teresa Anne Mullin

How Cystic Fibrosis Shaped My Childhood
With dry humor and sharp insights, Mullin describes her battles with the disease, teachers, fellow students, and even medical professionals who tried to hold her back from experiencing life. Alternately funny, frank, poignant, and gripping, *The Stones Applaud* reveals the talented young writer's fierce determination to live, thrive, and persevere. Whether writing about the joy of being accepted to prep school and Harvard University, the tragedies of others' deaths, or the pain of a broken friendship, Mullin never resorts to sentimentality or courts pity.

Beyond Breathing — By Margarete Cassalina

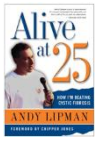
"Beyond Breathing" is a story of a mother's loss of her 13 year old daughter, Jena, to Cystic Fibrosis, a fatal genetic disease. Her journey takes you from unfathomable heartache to love and understanding of life's realities. Through her journey she learns that life lessons come from her children and the beauty of living and the power of love. In the span of one year she learns to go from depression and dependency to inner strength and the realization that love never ends and that there are no coincidences. That she is beyond just breathing.

Run, Amy, Run! — By Beth Huffman



Run, Amy, Run is written in memory of Amy, an inspirational young woman who refused to give in to cystic fibrosis, a ravaging disease that invaded her lungs at birth. By God's grace and Amy's determined spirit, her life span and quality of life far exceeded her doctors' expectations.

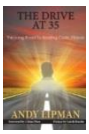
Alive at 25: *How I'm Beating Cystic Fibrosis* — By Andy Lipman



Afflicted with cystic fibrosis since birth, doctors told Andy Lipman's parents he'd be lucky to reach age 25. Over the years, however, Andy has found strength and determination in his athletic pursuits, has surprised his doctors, and defied the medical odds. On his 25th birthday, he picked up a pen and began to write his story. Now 28, healthy, happy, and very much alive, Andy shares his bittersweet story with humor and wit.

BOOKS

Drive at 35: *The Long Road to Beating Cystic Fibrosis* By Andy Lipman

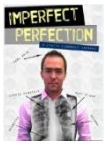


It is Andy's declaration that everyone, including medical professionals who told him he could not live past the age of 25, was wrong. This is the story of a competitive person with a life-threatening disease-the story of a person with hopes and dreams, just like everyone else, who must also deal with extraordinary circumstances.

Tyler's Mountain Magic By Malcolm Ater

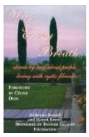
Although Tyler Moore was plagued by cystic fibrosis since early childhood, he refused to allow the progressive illness to disrupt his ambition of excelling at sports. Ater's *Tyler's Mountain Magic* is the story of how Tyler took his little junior high school and the town of Harpers Ferry on the most magical sports ride in West Virginia history.

Imperfect Perfection: *A Cystic Fibrosis Journey* By Jonathan Sacker



Jonathan Sacker was born with Cystic Fibrosis, a genetic disease which most effects the respiratory and digestive systems. *Imperfect Perfection* is a journey through the difficult and tumultuous battles that have resulted from this disease. With a comical and "laugh-at-yourself" style, Jonathan shares his life in an uplifting and positive manner with hope that each reader will find perfection within their own imperfection

With Every Breath By Katherine Russell and Margot Russell



Stories by and about people living with cystic fibrosis
Over 30,000 people in the US have cystic fibrosis, a life-threatening genetic disease that affects the lungs and digestive system. Physically, fighting it is a very perilous struggle. Emotionally, coping can oftentimes be even harder. *With Every Breath* consists of stories by and about people living with cystic fibrosis. Created to motivate, inspire, and generate positivity for those living with cystic fibrosis, this book is something you can open time and time again. Designed for all ages, this collection of diverse stories offers unique perspectives from patients, a CF doctor and nurse, and family members of those living with the illness.

Every Precious Breath By Tom Valenta

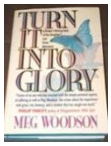
Inspirational Stories about Living with Cystic Fibrosis
In Every Precious Breath the author tells the story of his two grandsons and discovers that people living with CF and their families are very special people. Their ability to overcome hardships, endure pain and laugh at adversity is inspirational.

BOOKS

Cystic Fibrosis: *The Ultimate Teen Guide* — By Melanie Ann Apel

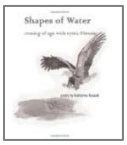
Cystic Fibrosis: The Ultimate Teen Guide leaves no aspect of this disease untold. Based on a series of interviews with young people with CF and their family members, the day-to-day dealings of life as a cystic fibrosis patient are described.

Turn It Into Glory — By Meg Woodson



A Mother's Moving Story of Her Daughter's Last Great Adventure
A mother's moving story of her daughter's last journey through hospitalization with cystic fibrosis to glory. A spiritual journey through a mother's grief and pain told in an unforgettable way.

Shapes of Water — By Katherine Russell

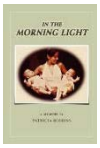


Coming of Age with Cystic Fibrosis
Shapes of Water is a collection of poems that journeys through one person's coming of age with cystic fibrosis, a genetic disease that inhibits mainly the lungs and digestive system. These are poems on love, family, loss, self-discovery, and coming-to-terms.

Rainbows, Butterflies & One Last Hug — By Peggy S. Imm-Anesi

A Mother's Spiritual Journey While Losing Two Children to Cystic Fibrosis
A look at life and the afterlife, after most of my immediate family died, including two kids to Cystic Fibrosis. I also lost parents, two siblings, a husband, and many others in a very short time. They have come to me and others after their deaths. I saw signs from the day they passed. Coping with Multiple Sclerosis while caring for so many others, you get through it by faith and believing life really is just a test run for what's in store for us all. I think after reading this book, you will see that nothing is impossible if you put your mind to your goals. Even through so much tragedy, you can still go on by helping others throughout what you have learned.

In the Morning Light — By Patricia Robbins



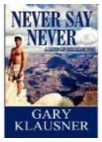
For almost twenty-five years, Jeff and Pat Robbins lived with the knowledge that their identical twin daughters, Charlotte and Vanessa, diagnosed with cystic fibrosis at age nine months, would die young. In spite of this overwhelming terminal illness, they raised their girls to be joyful, hopeful, full of life and most important, abundant in love. Choosing to live and work on a thoroughbred horse farm, living an idyllic, simple life focused on time spent together as a family, Charlotte and Vanessa grew up trusting in life. Secure in who they were and the bond they shared as twins allowed them to venture into life fearlessly to follow their dreams of acting, painting and writing five children's books together. For college, they moved three thousand miles away from home, where they found happiness and the love of two incredible young men. This is the story of their remarkable journey. Written by Pat, the girls' voices are threaded throughout each chapter, using their own words

taken from a documentary, a news program and their journals allowing them to tell their unique story of living and loving.

Seven Letters That Saved My Life — By Dottie Lessard

Seven Letters That Saved My Life takes us on Dottie's moving journey from conquering debilitating illness to literally climbing mountains with transplanted lungs. Combining personal insights with powerful motivational principles and affirmations, Dottie guides us in finding our own inner resources and inspiration.

Never Say Never: *A Life of Challenges* — By Gary Klausner

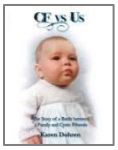


Never Say Never: A Life of Challenges is a memoir by Gary Klausner, who at the age of ten years old was diagnosed with Cystic Fibrosis and is about the challenges he has encountered throughout his life.

Salty Baby — By Orla Tinsley

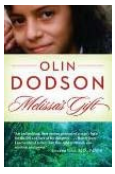
Orla Tinsley is well-known as a campaigner for the rights of people with Cystic Fibrosis in Ireland. In her memoir, she takes us on a journey into the inner world of a child whose home from home was hospital, yet who from an early age refused to allow her illness to define her. It is also a story about coming of age in today's Ireland, as Orla takes us through school, college and the pursuit of a dream to become a writer.

CF vs Us — By Karen Dohren



The Story of a Battle Between a Family and Cystic Fibrosis
Cystic Fibrosis is the United Kingdom's most common life-threatening inherited disease affecting over 8,000 people. This book tells the story of one family, our family. It recalls memories of living with something that turned our life upside down and inside out. It made us see life in a wholly different way. This is the story of how we faced this terrible disease and how we now are able to see the future in a more positive light.

Melissa's Gift — By Olin Dodson



In August, 1990, a solitary, unmarried man received a phone call from a stranger who informed him that he was the father of an eleven-year-old child who wanted to meet him. The girl's name was Melissa. She lived with her mother, a housekeeper, in a small town in western Costa Rica. Melissa had the incurable disease known as cystic fibrosis. Thus begins *Melissa's Gift*, Olin Dodson's account of his extraordinary relationship with his daughter. Written with elegance, beauty and power, *Melissa's Gift* is an unforgettable story and a deeply moving reading experience.

BOOKS

FICTION

Finding Home: *A Novel* — By Melanie Rose

When a car crash during a blizzard leaves a woman stranded in the New England countryside with no memory, she's taken in by Vincent, a banker whose adorable six-year-old daughter, Jadie, has cystic fibrosis and hasn't spoken since her sister died and her mother disappeared two years ago. But when this stranger arrives, calling herself Kate, Jadie suddenly begins speaking again—claiming that she can talk to her sister's ghost and that Kate is an angel sent to help them. As Kate struggles with startling flashbacks to a past life that doesn't seem to be her own, powerful questions arise: What happened to Jadie's mother? What secrets is Vincent hiding? Why has Jadie been silent for so long?

Drawing Breath — By Laurie Boris

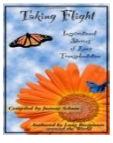
Art teacher Daniel Benedetto has cystic fibrosis. At thirty-four, he's already outlived his doctor's "expiration date," but that doesn't stop him from giving all he can to his students and his work. When he takes on Caitlin, his landlady's daughter, as a private student, the budding teen painter watches in torment as other people, especially women, treat Daniel like a freak because of his condition. To Caitlin, Daniel is not a disease, not someone to pity or take care of but someone to care for, a friend, and her first real crush. Convinced one of those women is about to hurt him, Caitlin makes one very bad decision.

A Time to Die (One Last Wish) — By Lurlene McDaniel

Sixteen-year-old Kara Fischer has cystic fibrosis and only months to live. But the close-knit bond she develops with Vince, who also has the disease, helps her come to terms with her own illness. Given one last wish, Kara wonders if miracles could really happen.

LUNG TRANSPLANTATION

Taking Flight — Compiled By Joanne Schum; Authored by Lung Recipients around the World



Inspirational Stories of Lung Transplantation

In this second volume of lung transplant stories (the first was her 2002 compilation of the similar title, Taking Flight), Joanne Schum, herself a lung transplant recipient now out 14 years, gathers another 166 stories of inspiration that should be the bible of required reading for anyone associated with lung transplantation, either as a patient, a candidate, a family support member or medical professional.

BOOKS

Second Wind — By Mary Jo Festle

Oral Histories of Lung Transplant Survivors

Many people have suffered from diseases that literally take their breath away. Second Wind relates the compelling stories of 'ordinary' Americans who sought a second chance through lung transplantation and the historical and socio-medical factors that affected them. Excerpts from oral history interviews reveal the physical and psychological challenges of deciding to pursue a transplant, waiting for a donor organ, and adapting to a new life with a lung from someone who died. Meaningful for those facing transplantation, their caregivers, scholars, and people outside the transplant community, Second Wind explores themes of uncertainty, timing, identity, coping, and quality of life.

The Lung Transplantation Handbook — By Karen A. Couture

A Guide for Patients

This comprehensive, 270-page book, written by lung transplant recipient and Second Wind member Karen A. Couture, covers the entire transplantation process from beginning to end for both lung and heart-lung transplants.

An Exercise Program for Individuals with Lung Disease — By Dr. William F. Brechue

An excellent manual written by Dr. William F Brechue with programs designed for those with lung disease. It has 70 pages and includes: Flexibility Program, Resistance Exercise Program, Machine Program, Dumbbell Program, Calisthenics Program, Aerobic Exercise Program.

Breathe and Let Go — By Gavin Maitland

A Lung Transplant Adventure

Breathe and Let Go is a dramatic tale of perseverance and survival. Faced with certain death from a progressive and debilitating lung disease, Gavin Maitland received a double lung transplant at Duke University Medical Center on March 14th, 2008. His determination to recover and compete in a triathlon only 13 months after his surgery is an uplifting story of resilience and determination. With down-to-earth humor and honesty, Maitland recounts his six-year odyssey from robust health in his mid-thirties through the decline and despair of failing lungs, through to a successful double lung transplant and beyond.

HOSPITALIZATION

Cystic fibrosis treatment can most often be managed at home, but an infection or other complication can arise, causing a CF patient to need to stay in a hospital. Being in the hospital is always stressful, but knowing what to expect can help make for a less frightening experience.

**Information on this page was found at: http://cysticfibrosis.about.com/od/livingwithcysticfibrosis/a/hospital.htm*

No Rest For the Weary

People are often frustrated at the lack of rest that they get in the hospital. For many people, it's hard to sleep in a strange bed. Add feeling miserable into the equation and it gets even harder. Not to mention the constant barrage of tests, medications, taking of vital signs, and various other activities that are going on. All of those activities are necessary for people in the hospital, but not very conducive to restful blocks of sleep. In order to get enough rest, expect sleep to be interrupted and grab as many naps as possible throughout the day.

Departure From Your Routine

A CF patient usually has a strict daily routine, so it may be distressing that the hospital staff is not following the usual medication and treatment routine. Some of the changes may be necessary because of the patient's condition, while other changes may be made to fit into the hospital's protocols or the nurse's schedule of tasks for the day. If you're concerned that a treatment is being missed, discuss concerns with your doctor or nurse to find out why.

Decrease in Appetite

Don't be surprised if a CF patient loses his appetite when in the hospital. The patient is not feeling well to begin with and is probably feeling scared and a bit out of sorts. It's no surprise that the likely unappetizing hospital food looks even less appetizing to him. However, if the patient is in the hospital for more than a few days and not eating enough to meet his needs, the doctor may order a temporary feeding tube to help the patient get necessary nutrition.

Isolation

When a CF patient arrives at the hospital, the nurses may do a nasal swab to check for certain organisms -- such as B. cepacia, P. aeruginosa, or MRSA -- that are common in people with cystic fibrosis. Depending on the hospital policy, the patient may be placed on 'contact precautions' until the results of the test are negative. If the results come back positive, the CF patient will be on contact precautions for the remainder of his hospital stay. This means that nurses and other caregivers will wear gowns and gloves when they enter the room, and he will have to stay in his room unless he is going to another department for a test or procedure. For the patient's protection, he may be required to wear a mask whenever he leaves the room even if his cultures are negative.

Intravenous Lines

The CF patient will probably have an intravenous line (IV) so that he can receive medications and fluids during his hospital stay. One of the most common reasons for people with cystic fibrosis to go to the hospital is to receive IV antibiotics to fight an infection. Many of these antibiotics are irritating to the small,

superficial veins. If a CF patient is going to be getting an irritating antibiotic, or if he is going to be getting antibiotics for several weeks, his doctor may order a deeper, longer-lasting IV line called a PICC.

Step-by-Step

Johns Hopkins created a thorough packet of what to expect when you check your child (or yourself) into the hospital. While you may not utilize Johns Hopkins services, the information is still a valuable resource. You can find "*A Guide to Inpatient Care for Cystic Fibrosis Families*" here: www.hopkinscf.org/docs_shared/Inpatient%20Guide_April%202011.pdf

Packing Checklist

This checklist is compiled of recommendations from other CF parents at Johns Hopkins. It is not all-inclusive but is meant to help you think about what to bring for your child's inpatient stay.

- Insurance cards, medication lists, important legal documents (e.g., custody, etc.)
- Comfy clothes for child and parents (sweats, zip up hoodies)
- Socks, slippers, slipper socks
- Pajamas/robe
- Exercise/gym clothes and shoes for physical therapy
- Toiletries
- Airway clearance devices (Acapella®, Vest®, inCourage™ system)
- Books, crosswords, puzzle books, etc.
- iPods, mp3 players, and chargers
- Cell phone and charger
- Laptop computer with Skype™ access, and charger
- Favorite pillow and blanket, pillow and blanket for parent(s)
- Arts and crafts supplies
- Favorite stuffed animal
- Card and board games
- School work
- DVDs
- Blackout material to darken room
- Earplugs and eye mask
- Empty suitcase/duffle bag
- Cooler that can be filled with ice for perishables (request ice from RN on floor)
- Extra snacks, microwave meals
- Handheld game systems

NEWSLETTERS

Breathing Room

www.thebreathingroom.org

The Breathing Room was developed to serve the Cystic Fibrosis community. They believe that organ transplant, palliative care and hospice care are issues that all people with CF will face, in one form or another, at some time or another. It is the goal of *The Breathing Room* to address these profound emotional issues, not to offer advice or medical consultation, but to present personal experiences and resources for community members to utilize when face to face with such important issues.

Candid Facts

www.cysticfibrosis.ca/en/publications/Newsletters.php

Candid Facts – Cystic Fibrosis Canada's quarterly newsletter – includes up-to-date news about CF research, treatment, special events, and human interest stories.

Circle of Friends

www.cysticfibrosis.ca/en/publications/Newsletters.php

Circle of Friends – Cystic Fibrosis Canada's biannual national newsletter produced by their Adult CF Committee – addresses the needs and concerns of Canadian adults with cystic fibrosis.

Cochrane Cystic Fibrosis and Genetic Disorders (CFGD) Group

http://cfgd.cochrane.org/newsletters

The Cochrane Cystic Fibrosis & Genetic Disorders Group consists of a team of people who are interested in producing high quality systematic reviews of controlled clinical trials in cystic fibrosis (CF) and other genetic disorders. The Editorial Base is in Liverpool, UK.

The Connection

www.foundcare.com/fcnews/

Foundation Care's mission is to serve as a full service retail pharmacy that provides specialized patient care and personalized service from a professional staff by focusing on quality, respect, and commitment to care.

Connections

www.cff.org/signup/

Connections is an e-newsletter provided by the Cystic Fibrosis Foundation.

Cystic Fibrosis Worldwide

www.cfww.org/pub

Dedicated to improving quality of life and life expectancy for persons living with cystic fibrosis globally. CFW has over 60 member countries with a number of members coming from developing parts of the world. With these new memberships comes an awareness of the desperate situation facing those who have cystic fibrosis, caregivers or medical professionals in developing countries.

HomeLine

www.cfservicespharmacy.com/PatientEducation/HomeLineNewsLetter/HomeLine/

HomeLine is a free quarterly newsletter published by the Cystic Fibrosis Services Pharmacy with information about new therapies and advances in cystic fibrosis treatment and care.

The Living Breath Foundation Newsletter

http://www.thelivingbreathfoundation.com/newsletter.html

The Living Breath Foundation periodically releases newsletters to inform its supporters of progress made on various projects.

The Servers e-Patient Flash

www.cysticfibrosis.com/newsletter.cfm

Our mission is to serve as a full service retail pharmacy that provides specialized patient care and personalized service from a professional staff by focusing on quality, respect, and commitment to care.

USACFA: CF Roundtable

www.cfroundtable.com/

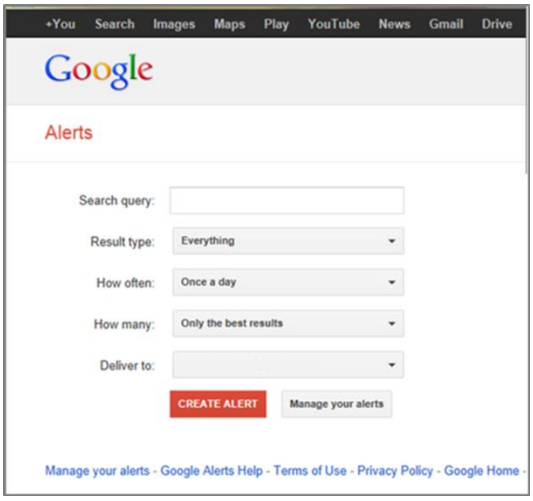
The United States Adult Cystic Fibrosis Association Inc. (USACFA) is a non-profit, 501(c)(3) organization, run by 12 volunteer Directors who all have CF. Since 1990, USACFA has published a quarterly newsletter, CF Roundtable, offering hope, support, and news in the world of cystic fibrosis.

Another great way to follow CF News is to set up "**Google Alerts**" and have stories sent to you as often as you want directly to your email!

Google Alerts monitor the Web for interesting new content. Google Alerts are email updates of the latest relevant Google results (web, news, etc.) based on your queries.

Enter a search query you wish to monitor. You will see a preview of the type of results you'll receive. Some handy uses of Google Alerts include:

- •monitoring a developing news story
- •keeping current on a competitor or industry
- •getting the latest on a celebrity or event
- •keeping tabs on your favorite sports teams



TRAVEL CHECKLIST

CF patients have created a wonderfully open online conversation and are willing to share a lot of "intimate" details if they feel it will benefit their peers. They made this travel list possible!

PRIOR TO TRAVEL

- ☐ Check in with your CF team
  - *Ask advice.*
  - *Discuss concerns.*
  - *Look for local health providers in your destination city.*
  - *How to provide emergency care during trip if needed.*
  - *Flying? Flight oxygen test?*
- ☐ Get a signed letter from your doctor explaining CF and list your medications and equipment.
  Traveling abroad? Have it translated into the predominant language of your destination city.
- ☐ Schedule all of your vaccines four to six weeks before traveling
  (some take time to take effect)
- ☐ Set an itinerary.
  Always make sure you've planned for your treatments. You shouldn't have to feel rushed or that you are inconveniencing anyone.
- ☐ Travel Insurance
  Check with your personal provider first and then also look into specific insurance. Make sure the plan includes medical coverage for existing conditions. Also, confirm that you are able to cancel for unexpected health reasons.
- ☐ Backup Plans
  Make sure you're listening to your body in the weeks leading up to your travel plans. If you are getting sick, it's better to cancel your trip and reschedule when you're feeling better.
- ☐ Research your destination – is it CF friendly?
  - *Is it hot? Sunscreen and salt tablets a must! Also, make sure your drugs are refrigerated.*
  - *Elevation?*
  - *Pollution Level?*
- ☐ Try to exercise regularly before your trip
  (ask your physician if this is right for you)
- ☐ Check on your transportation carrier
  Travelers with special healthcare needs should provide documents and requirements regarding the storage of your medical equipment.
- ☐ Accommodations
  - *Smoke free room?*
  - *Med storage – mini bar? Use of hotel kitchen? Can they supply a mini fridge?*
- ☐ Educate your traveling partners and people you meet along the way…
  so that they can be your advocate when you cannot.
- ☐ Check in to special rates at local tourist attractions for customers with special needs

TRAVEL CHECKLIST

TO PACK

- [ ] Doctor's Letter
  **A great suggestion, in case of situations out of your control, is to laminate all of your personal information. That way it will be easy to read and is also protected.*
  **__INCLUDE__: Physicians Name, Physicians Number, Healthcare Provider, Medical Diagnosis, Medical History, Allergies, List of Medications – (list the trade name and generic drug name and include supplements, syringes, needles) – for the airport security, Dosages, Insurance Card Copies*
- [ ] Provide list of medications to the airport/airline.
  Providing this list to the airport/airline, could possibly reduce extra baggage costs because of its medical necessity. Contact your transportation carrier to find out.
- [ ] Email yourself a PDF of all forms.
  This will come in handy if your physical copy is damage or misplaced.
- [ ] Phone number and address reference list
- [ ] Nebulizer
- [ ] Air compressor *(if applicable)*
- [ ] Extra Batteries for nebulizer *(if applicable)*
- [ ] Salt tablets *(or other electrolyte supplementation)*
- [ ] Insulated thermal bag/thermos
- [ ] Dust/surgical mask
- [ ] Hand sanitizer and disinfectant wipes
- [ ] Insulin *(stored cool)*
- [ ] Sun screen *(especially if you're on antibiotics)*
- [ ] Medications
  Include your personal list of daily meds. (Ex: Pulmozyne, Hypersal, etc)
- [ ] Syringes *(if applicable)*
- [ ] Needles *(if applicable)*
- [ ] Alcohol
- [ ] Vest
- [ ] I.C.E. Bag *(In Case of Emergency)*
  Pack a few of your meds that you don't use on a regular basis, just in case your body calls for it.

TRAVELING ABROAD

- [ ] Passport and/or Visa
- [ ] Immunizations Record
- [ ] Electrical plug adapters
- [ ] List of CF Centers with addresses and phone numbers.
- [ ] Explanation of CF and treatments
  (translated into destination city's predominant language, if applicable)
- [ ] Consider the country and its smoking policies.
  Smoking is more popular in European countries than the U.S. Research restaurants and hotels. See if there are "allergy-free" accommodations.
- [ ] Contact the European CF Society
  (they have listings for most CF centers in Europe)
- [ ] Think about renting a vest.
  (it could be expensive)
- [ ] Bring batteries for your nebulizer *(if possible).*
  Converters may make your nebulizers less efficient.

TRAVEL CHECKLIST

FLYING

☐ Check the current TSA guidelines.
Find out what you can and cannot bring on the plane. Call the "TSA Cares" hotline to speak to a representative: (toll-free 1-855-787-2227) or visit their website at http://www.tsa.gov/travelers/airtravel/disabilityandmedicalneeds/tsa_cares.shtm

SPECIAL CIRCUMSTANCES

☐ Travel with oxygen
Make special arrangements prior to traveling. You will need to contact your airline and notify them of your situation, special permissions will be needed. Also, plan where and how you'll receive oxygen at your destination. Just be aware, this can get expensive.

Visit the CDC guidelines to find out more information on international travel guidelines, warnings, and health notices: http://wwwnc.cdc.gov/travel/

EDUCATIONAL AND HOW TO VIDEOS

From Boomer Esiason Foundation

Almost 200 videos about health, exercise and motivation for CF patients.
**To view, visit: www.youtube.com/drimington*

From CF Living

Accepting and Living Your Life with CF

Telling your friends or new acquaintances that you have CF can be difficult. In this video, CF patients and caregivers share their stories of accepting CF and overcoming their fears of opening up to others about their disease.
CFLiving.com/AcceptingCF

Adapting to CF Normal

Many people with CF struggle to find balance in living a "normal" life and maintaining good CF care. Check out this new video where CF patients share their stories on how they have learned to adapt to their CF normal.
CFLiving.com/CFnormal

Establishing Healthy CF Care Habits

Keeping up with your CF care can be hard, but having a routine can help you stay on top of your treatments. In this video, hear from CF patients and caregivers who share tips on treatment schedules, good eating habits and the importance of exercise.
CFliving.com/healthyCFhabits

From the Cystic Fibrosis Trust

Getting Nosey About CF

A short film made for the Cystic Fibrosis Trust (www.cftrust.org.uk) by Absolutely Cuckoo, to help children with Cystic Fibrosis understand their condition and to explain to other children what Cystic Fibrosis is.
http://www.youtube.com/watch?v=WuI72eMrIQI

From Foundation Care Pharmacy

How To… Use. Clean. Disinfect. (Trio®)

Learn how to clean, disinfect and use your Trio® nebulizer with the help of this step-by-step instructional video!

How To… Use. Clean. Disinfect. (Altera®)

Learn how to clean, disinfect and use your Altera® nebulizer with the help of this step-by-step instructional video!

**View them online by visiting: www.FoundCare.com/ a-interact-with-fc-secure*

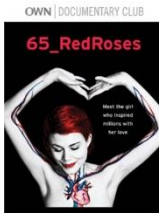
DOCUMENTARIES AND FICTIONAL FILMS

The Power of Two (2011)

Inspired by their 2007 memoir, *The Power Of Two* offers an intimate portrayal of the bond between half-Japanese twin sisters Anabel Stenzel and Isabel Stenzel Byrnes, their battle with the fatal genetic disease cystic fibrosis (CF) and miraculous survival through double lung transplants. Defying all odds, Ana and Isa have emerged as authors, athletes and global advocates for organ donation, and their connection to the CF and transplant communities provides rare insight into the struggles — and overlooked joys — of chronic illness.

Miracle on South Street (2012)

In 1992, my neighbor and close family friend Julie D'Agostino was born with Cystic Fibrosis, a potentially life-threatening genetic disease. In and out of hospitals since she was a child, things took a turn for the worse right before Julie's 19th birthday.
This documentary chronicles Julie and her family's life-long battle with the disease, leading up to the recent life-saving double lung transplant surgery. It also documents our neighborhood's strength as well as the support from the entire community. As a filmmaker, I felt a responsibility to tell Julie's courageous story and shed light on the importance of organ donation.

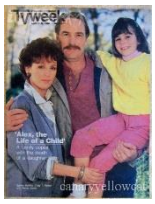


65_RedRoses (2009)

Redefining the traditional scope of documentary film in an electronic age, *65_RedRoses* leaves viewers with a new appreciation of life and the digital world. This personal and touching journey takes an unflinching look into the lives of Eva Markvoort and her two online friends who are all battling cystic fibrosis (CF) – a fatal genetic disease affecting the lungs and digestive system. Unable to meet in person because of the spread of infections and super bugs, the girls have become each other's lifelines through the Internet, providing unconditional love, support and understanding long after visiting hours are over. Now at a critical turning point in their lives, the film travels the distance the friends cannot go themselves, capturing the compelling and often heartbreaking realities they face, just trying to take each breath.

Foreverland (2012)

Foreverland tells the story of Will Valley, a young man stricken with Cystic Fibrosis, a terminal illness, who is tasked with delivering his friend's ashes to a legendary healing shrine in Mexico. Joined by the sister of his fallen friend, Will embarks on an epic journey down the Pacific Coast Highway to the desert heart of Baja, encountering a memorable cast of characters along the way. In the spirit of Into the Wild and Little Miss Sunshine, it's about dreams and the courage to pursue them, about hope, laughter, and life's small miracles.

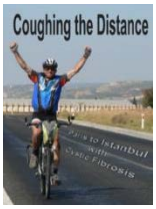


Alex: The Life of a Child (TV 1986)

Alex: The Life of a Child is based on the true story of *Sports Illustrated* writer Frank Deford and his dying 8-year-old daughter Alex. Craig T. Nelson plays Deford and Gennie James is Alex, both of whom come to grips in different ways with Alex's fatal cystic fibrosis. A subplot involves the torment of Deford's wife (Bonnie Bedelia), who wonders whether she should adopt a child after Alex's death in 1980. *Alex: The Life of a Child* is effective, but not as well made as its subject matter deserves. Better examples of this particular TV-movie genre include *Death be Not Proud* (75), based on author John Gunther's recollections of his son's struggle against a degenerative brain tumor, and *Mary White* (77) the story of a personal tragedy in the life of Kansas journalist William Allen White.

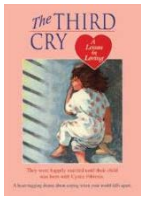
My Flesh and Blood (2003)

The documentary takes an in-depth at the Tom Family which mostly consists of children that were rejected by their birth families due to mental or physical disabilities. The film is broken up into seasons starting out with family taking part in Halloween in the fall and ending in the summer of the upcoming year. The family's unconventional home-life becomes a foundation for the supports, challenges, and successes that they face daily.



Coughing the Distance with Cystic Fibrosis (2008)

Walter, a 42 years young person with Cystic Fibrosis, made a bicycle trip across Europe to inspire other people with Cystic Fibrosis, their friends and families as well as anyone else with a disability. Walter is a 42 year old man who decides to cycle from Paris to Istanbul. Through a dozen European countries, covering 4000+ kilometers in 72 days with the help of a team of friends, 1500+ pills, and only half normal lung capacity.

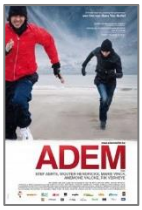


The Third Cry (1989)

Mike and Sherry's future together looked bright until their first child was born with Cystic Fibrosis, a disease that would almost certainly kill the child in her teens. In this inspiring drama, young parents are pushed to the edge and find the strength not only to accept a second child with the same disease, but also to adopt a third. This drama speaks powerfully to all those facing overwhelming difficulties.

RECOMMENDED FOR ADULTS ONLY

**These films contain subject matter that can be offensive and inappropriate for children.*



Oxygen (2010)

Oxygen, a Dutch-Belgian film about young people trying to figure out how to live with cystic fibrosis, won two prizes at the Montreal World Film Festival, including the Grand Prix des Americas. The feature film debut by Belgian director Hans Van Nuffel also won the Ecumenical Award at the festival. Oxygen follows two young men who suffer from the disease: one an athlete, another who hangs out with a gang of hoodlums.

Excision (2012)

A surgery-obsessed teen struggles with her outcast status while plotting to lose her virginity and save her sister from the ravaging effects of cystic fibrosis in this genre-bending shocker from writer/director Richard Bates, Jr. Pauline (Annalynne McCord) is a pretty young girl whose penchant for picking scabs has escalated into a fanatical obsession with the flesh. Recognizing this, Pauline's stern mother insists that the young girl visit the church therapist for counseling. Incensed at the prospect of being judged by a religious hypocrite, Pauline only delves deeper into her visceral fantasies while concocting an ingenious plan to impress her mother. Meanwhile, as Pauline begins devising ways to combat her younger sister's cystic fibrosis, her adolescent hormones kick into overdrive. Traci Lords and John Waters co-star.

Last Breath (1997)

Chrystie Devoe is sick, she has cystic fibrosis, and she also has a rare blood type. Her husband, schoolteacher Martin is looking for candidates with her blood type that can possibly help her, and among them is attractive Gale Pullman.

NOTABLE TV EPISODES

Breathless Bride: Dying to Live (TLC)	Documentary	Aired February 29, 2012
Dr. Phil	"Surviving the Worst"	Aired June 5, 2003
Dying Young (Current TV)	Documentary short	Aired May 27, 2008
E.R. (NBC)	"Whose Appy Now?"	Season 3: Episode 14
Grey's Anatomy (ABC)	"Deny, Deny, Deny" "Not Responsible"	Season 2: Episode 4 Season 7: Episode 16
House M.D. (Fox)	"The Greater Good"	Season 5: Episode 14
Nurse Jackie (Showtime)	"Twitter"	Season 2: Episode 2
NY Med (ABC)		Season 1: Episode 6
Overhaulin' (Discovery)	"'65 Bug"	Season 6: Episode 4
Say Yes to the Dress (TLC)	"New Beginning"	Season 8: Episode 18

THE CF LEGAL INFORMATION HOTLINE

The Cystic Fibrosis Foundation is proud to sponsor the CF Legal Information Hotline through a grant from Novartis Pharmaceuticals Corporation. It provides free information about the laws that protect the rights of individuals with cystic fibrosis (CF). It serves as a resource for CF Care Centers, individuals with CF, and their families. Information is available regarding:

- Obtaining health insurance
- Access to health insurance under the Health Insurance Portability and Accountability Act (HIPAA)
- Extending health insurance coverage under COBRA
- Insurance coverage issues
- Social Security Disability Insurance benefits
- Supplemental Security Income (SSI) benefits
- Medicare and Medicaid coverage
- Employment issues for people with CF, including protections under the Americans with Disabilities Act (ADA)
- School laws to assist children with CF in public elementary and secondary schools through the Individuals with Disabilities Education Act (IDEA)
- Protections for students in elementary school through college and beyond under the Rehabilitation Act of 1973, Section 504
- Unpaid time off from work under the Family Medical Leave Act (FMLA)

**The CF Legal Information Hotline is an information resource only. The Hotline does not provide legal representation for callers. All calls are confidential.*

***More information regarding the CF Legal Information Hotline can be found at:*
www.cff.org/LivingWithCF/AssistanceResources/CFLegalHotline/

LOCATE A CF CARE CENTER

The high quality of specialized care available throughout the care center network has led to the improved length and quality of life for people with CF. Located at teaching and community hospitals across the country, these care centers offer the best care, treatments, and support for those with CF.

To locate a CF Care Center, visit the CF Foundation's website:
http://www.cff.org/LivingWithCF/CareCenterNetwork/CFFoundation-accreditedCareCenters/

*****Please Note****: The list provided by the CF Foundation contains only CF Foundation-accredited centers. There are hospitals and clinics not accredited by the CF Foundation that also specialize in cystic fibrosis. Check with your local hospital to find out if they can help.*

DOWNLOADABLE RESOURCES

From CysticLife

To download the following handouts, please visit: http://www.cysticlife.org/cystic-fibrosis-reading-materials.php

- *Exercising with Cystic Fibrosis*
  - Adding exercise to your CF care plan is crucial. This handout explores the benefits of exercise for people with CF and how to go about starting your own exercise plan.
- *Snack Your Way to Improved Lung Function*
  - People with CF need to consume a lot of calories. This handout is a guide to easy 100, 200, 300, and 400-calorie snacks.
- *Taking Cystic Fibrosis to School*
  - Learn how to work with your child's school when it comes to CF. This handout helps explain what a 504 plan is and how you can set one up for your child.

From American Lung Association

This report can be downloaded at: http://www.lung.org/finding-cures/our-research/solddc-index.html

- *State of Lung Disease in Diverse Communities 2010*

From American Thoracic Society

To download this chapter, please visit: http://thoracic.org/education/breathing-in-america/index.php

- *Chapter 7: Cystic Fibrosis (pages 67-75)*
  - In 2010, the ATS published Breathing in America: Diseases, Progress, and Hope, a book that explores the nature and causes of pulmonary, critical care and sleep disorders, their prevalence and burden, the benefits research has brought and the research challenges that remain.

From U.S. National Library of Medicine

- Find additional information, videos and interactive tutorials on NLM's website: http://www.nlm.nih.gov/medlineplus/tutorials/cysticfibrosis/htm/index.htm

SCHOLARSHIPS

College costs are expensive and *(usually)* a 4-year time commitment. However, cystic fibrosis (CF) treatment is a life-long commitment -- and even more expensive per year than a secondary education.

Combined, college and CF can create astronomical living costs. If you are wondering how you will ever be able to keep your head above water without jeopardizing treatments AND attend a 4-year college or university, you are not alone. The good news is that there are foundations, scholarships and grants set up specifically to help cystic fibrosis patients and their families continue their educations.

**Not all scholarships are offered annually. Please use the contact information provided with each scholarship description to find out if the scholarship is available to you.*

**This is not a comprehensive list. Always check with your university of choice regarding its specific scholarships and financial aid requirements.*

The Angela Brooke Warner CF Scholarship Endowment Fund

ABOUT THE SCHOLARSHIP:
The Angela Brooke Warner CF Scholarship Endowment Fund was established in 2005 by The Angela Warner Foundation to honor and memorialize the beautiful life of Angela Brooke Warner who passed away on February 6, 2003, at the age of 21 after a courageous, lifelong battle against cystic fibrosis.

REQUIREMENTS:

- Applicants must be a full-time undergraduate or professional school student at the University of Minnesota.
- Preference will be given to a student or students with cystic fibrosis.
- The scholarship may be awarded annually or renewed for a maximum of four years.
- Applicants must be in good academic standing.

AMOUNT: Varies.

DEADLINE: N/A

CONTACT:

The Angela Warner Foundation
801 Twelve Oaks Center Drive
Suite 826
Wayzata, MN 55391
Phone: 952-473-1116
Fax: 952-473-3129
Email: don@angelawarnerfoundation.org

WEBSITE:

- https://diversity.umn.edu/disability/disabilityrelatedscholarships
- http://www.angelawarnerfoundation.org/scholarships/

Anita Giampalmi Cystic Fibrosis Scholarship at Michigan State University

ABOUT THE SCHOLARSHIP:
The Anita Giampalmi Cystic Fibrosis (CF) Scholarship is awarded through the Resource Center for Persons with Disabilities (RCPD) in memory and recognition of Anita Giampalmi. The scholarship provides a monetary reward as well as recognition of efforts toward the achievement of an educational program at MSU for a student who has cystic fibrosis.

REQUIREMENTS:

- Demonstrated academic achievement
- Academic references
- Educational and life goals
- Leadership and other personal qualities
- A written essay

AMOUNT: Up to $1,500.

DEADLINE: Scholarship applications are welcomed throughout the year, but strongly encouraged between December and February.

CONTACT:

Resource Center for Persons with Disabilities (RCPD)
Bessey Hall

434 Farm Lane, #120
Michigan State University
East Lansing, MI 48824-1033
Phone: (517) 884-RCPD (4-7273)
TTY: (517) 355-1293
Fax: (517) 432-3191

WEBSITE: https://www.rcpd.msu.edu/scholarships/cfs

Barbara J. Brenner Tremble Memorial Scholarship

ABOUT THE SCHOLARSHIP:
The Barbara Brenner Tremble Scholarship was established in 1988 at the University of Wisconsin – Eau Claire. Despite battling cystic fibrosis her entire life, Barbara was dedicated to learning and was a positive influence on all those around her. She valued the importance of maintaining and making the most of good health.

REQUIREMENTS:
Student has a physical disability with preference for a student who has cystic fibrosis. Student is in good academic standing or admitted with full standing in the case of freshmen or transfer students. Preference is to be given to students with financial need. Preference is to be given to juniors and seniors.

AMOUNT: $500

DEADLINE: May 1

CONTACT:

University of Wisconsin – Eau Claire
Office of Financial Aid
Schofield 115
Eau Claire, WI 54702
Phone: 715-836-3373
Email: finaid@uwec.edu

WEBSITE: http://www.uwec.edu/Multicultural/student/scholarship.htm

BEF General Academic Scholarships

ABOUT THE SCHOLARSHIP:
The Boomer Esiason Foundation's General Academic Scholarships assist CF patients pursuing undergraduate and graduate degrees. Grants are awarded quarterly on the basis of demonstrated need and academic accomplishment. They are made directly to the academic institution to assist in covering the cost of tuition and fees. This scholarship is for one year only.

REQUIREMENTS:
The BEF Scholarship Program committee considers the applicant's scholastic ability, character, leadership potential, service to the community and need for financial assistance. Once candidates have been selected as semi-finalists, they will be granted a phone interview with a committee member.

- Application
- Essay
- Recent photo
- Letter from physician (on letterhead) confirming CF diagnosis and therapy routine
- Transcript (high school, college and/or graduate school)

- Letter of acceptance from academic institution
- Detailed breakdown of tuition costs from academic institution
- W2 form for both parents

AMOUNT: $500 to $2,500
DEADLINE: March 15, June 15, September 15 and December 15
CONTACT:

Boomer Esiason Foundation
c/o Jerry Cahill
483 10th Avenue, Suite 300
New York, NY 10018
Email: jcahill@esiason.org

WEBSITE: http://esiason.org/thriving-with-cf/scholarships/bef-general-academic-scholarships.php

The Bonnell Foundation: Living with Cystic Fibrosis Scholarship

ABOUT THE SCHOLARSHIP:
The Bonnell Foundation: Living with Cystic Fibrosis has established a scholarship program to assist students with Cystic Fibrosis who plan to continue their education in college. Marge Carmona Education Scholarships are administered by The Bonnell Foundation. Awards are granted without regard to race, color, creed, religion, sexual orientation, gender or national origin. Awards are for undergraduate study only.

REQUIREMENTS:

- Have received an acceptance letter or confirmation from the college they intend to enroll in
- Children, age 25 and under, who have been diagnosed with Cystic Fibrosis.
- Students with a 3.0 or higher GPA
- Interested students must provide a hard or digital copy of their application.
- Provide a typed essay describing how Cystic Fibrosis has impacted your life and the life of your family, in 300 words or less.
- Provide a copy of your acceptance letter, or confirmation of your acceptance, or proof of enrollment for the upcoming Fall semester to a college or university.
- Provide a copy of your most recent transcript with your GPA.
- Provide a recent photograph

AMOUNT: Up to $2,500
DEADLINE: June 30, 2013
CONTACT:

P.O. Box 1215
Royal Oak, MI 48068
Phone: 248-860-3899
Email: info@roadmaptocf.org

WEBSITE: http://thebonnellfoundation.org/

Bonnie Strangio Education Scholarship

ABOUT THE SCHOLARSHIP:
The Bonnie Strangio Education Scholarship was established in 2005 to honor the memory of Bonnie Strangio. The scholarship is awarded to a person living with cystic fibrosis who, like Bonnie, has an upbeat personality and "can-do" attitude, and shows a tremendous passion for life in achieving their goals despite battling CF.

REQUIREMENTS:

Applicants must be an undergraduate or graduate student who has cystic fibrosis and whose service and commitment to the prevention and cure of CF is exemplary. The scholarship committee will select finalists, who will be interviewed thereafter. The award recipient will be chosen by a majority vote.

- Application
- Essay
- Recent photo
- Letter from physician (on letterhead) confirming CF diagnosis and therapy routine
- Transcript (high school, college and/or graduate school)
- Letter of acceptance from academic institution
- Detailed breakdown of tuition costs from academic institution
- W2 form for both parents

AMOUNT: $500 to $1,000

DEADLINE: June 21, 2013

CONTACT:

Boomer Esiason Foundation
c/o Jerry Cahill
483 10th Avenue, Suite 300
New York, NY 10018
Email: jcahill@esiason.org

WEBSITE: http://esiason.org/thriving-with-cf/scholarships/bonnie-strangio-education-scholarship.php

CFCareForward Scholarship

ABOUT THE SCHOLARSHIP:

Recognizing the financial burdens that exist for many CF families, Abbott developed the CFCareForward Scholarship to honor young adults with CF as they pursue goals of higher education. Since 1993, Abbott has awarded scholarship funds through this program totaling more than $2.3 million.

REQUIREMENTS:

This program is designed for students with CF pursuing an undergraduate degree *(Associate's/2-year college, Bachelor's/4-year college, trade/vocational school)* or graduate degree *(Master's, M.D., J.D., Doctorate's)* during the upcoming academic year. Applicants must have completed high school or obtained General Educational Development *(GED)* certification on or before the summer prior to the new academic year. It is not necessary for applicants to currently take any medicine or product marketed by Abbott, and this will not be a consideration in the recipient selection criteria.

Recipients are selected based on established criteria, including:

- Academic record
- Extracurricular activities
- Essay
- Creative presentation

AMOUNT:

- Forty Scholarship recipients will be chosen by Abbott to receive the $2,500 **CF**CareForward Scholarship.
- Two of those recipients (an undergraduate and a graduate student) will receive an additional $17,500 (totalling $20,000) after a public vote has been completed and results determined to be valid.

DEADLINE: Varies.
CONTACT:

Ruder Finn
ATTN: 2012 CFCareForward Scholarship Program
301 East 57th Street
New York, NY 10022
Email: info@cfcareforwardscholarship.com

WEBSITE: www.cfcareforwardscholarship.com

Cystic Fibrosis Scholarship Foundation (CFSF)

ABOUT THE SCHOLARSHIP:

The mission of the Cystic Fibrosis Scholarship Foundation (CFSF) is to provide an opportunity for young adults with CF to further their education at a college or vocational school. This possibility is often out of reach for families with CF children because of the high cost of medical care from the time these students were babies. We at CFSF believe in the future of these young adults, their ability to achieve personal and educational goals, and their importance in making a long-term contribution to society on all levels.

REQUIREMENTS:

The program is available to those who will be enrolled in an undergraduate program or vocational school in the fall of 2013. Scholarships will be awarded based on a combination of financial need, academic achievement, and leadership. Awards may be used for tuition, books, and room and board. Awards will be sent directly to the institution that the student is attending. Students can reapply the following year for an additional award, but there is no guarantee they will receive one.

- Completed application
- Tax return information
- Doctor's note
- College or vocational school transcript
- References

AMOUNT: Both single year and multi-year awards are made, generally for $1000 per year.
DEADLINE: March 18, 2013
CONTACT:

Cystic Fibrosis Scholarship Foundation
1555 Sherman Avenue, #116
Evanston, IL 60201
Phone: 847-328-0127
Email: mkbcfsf@aol.com

WEBSITE: http://cfscholarship.org/applications/

Dana Walters Scholarship Foundation

ABOUT THE SCHOLARSHIP:

The purpose of the Dana Walters Scholarship is to honor the dedication and commitment that Dana felt toward the educational process. This program is designed to help students purchase books, pay mandatory fees and other necessary dues to be able to follow their chosen course of study. By removing the financial burden from the family, students should be able to concentrate on their studies and be successful.

REQUIREMENTS:

- Be a graduating senior or already have a high school diploma
- Achieve an SAT score of no less than 900 combined, or an ACT score of no less than 21, if required by the school you are attending.
- A GPA of 2.70 or in the top 30% of your class
- Have Cystic Fibrosis or a member of your immediate family have CF
- Live in the State of Georgia
- Have three written references returned with your application package
- You don't have to have Cystic Fibrosis in order to qualify for the scholarship. You need only be an immediate member of a family with a person with CF.

AMOUNT: N/A
DEADLINE: N/A
CONTACT:

Dana Walters Scholarship Foundation
P.O. Box 723243
Atlanta, GA 31139
Phone: 770-436-0190
Email: sonickaren@aol.com

WEBSITE: http://www.dwscholarship.com/index.html

The Elizabeth Lulu Scholarship Foundation

ABOUT THE SCHOLARSHIP:
The Elizabeth Lulu Scholarship Foundation was founded in 2006 after Elizabeth Lulu passed away at age 13 due to complications from Cystic Fibrosis. The ELSF honors the memory of Elizabeth, who fought gallantly against the disease and never let her diagnosis define her life. The ELSF awards money to teens diagnosed with Cystic Fibrosis as an extra motivation to continue their individual educational goals.

REQUIREMENTS:

- One-page essay
- Copy of high school transcripts
- Doctor's note confirming CF diagnosis
- Three references
- Recent photo of applicant

AMOUNT: Up to $1,000
DEADLINE: N/A
CONTACT:

The Elizabeth Lulu Scholarship Foundation
c/o Beth and Allen Lulu
1760 W. 25th St.
Los Angeles, CA 90018
Fax: 323-734-5858
Email: elizabethluluscholarship@gmail.com

WEBSITE: www.lizzielulu.org/

Elizabeth Nash Foundation Scholarship Program

ABOUT THE SCHOLARSHIP:
The Elizabeth Nash Foundation awards scholarships to assist persons with Cystic Fibrosis (CF) to pursue undergraduate and graduate degrees.

REQUIREMENTS:
The Elizabeth Nash Foundation Scholarship program is open to individuals with CF who are in-going or current undergraduate or graduate students at an accredited US-based college or university. Given limited resources, the program is currently only open to US citizens. Funds to support Associate Degrees are not currently available. To be considered complete, all applications must include the following

- Complete, signed application.
- Essay question response.
- A detailed list of annual tuition and fees for your college/university.
- A detailed list of all sources of financial aid/support already awarded (e.g. scholarships, grants, fellowships, work/study, contributions from family, etc.)
- A photocopy of most recent Student Aid Report (SAR), the Department of Education's response to your Free Application for Federal Student Aid (FAFSA).
- A copy of your most recent financial aid award notice.
- A letter of recommendation from a teacher or a supervisor or coach involved with your volunteer or extracurricular activities.
- A letter from your doctor or social worker confirming a diagnosis of cystic fibrosis.
- For ingoing freshmen - An official transcript from your high school and an acceptance letter or confirmation of enrollment from your college/university.
- For current college students – An official transcript from your college/university.
- A self-addressed stamped envelope (letter size).

AMOUNT: $1,000-$2,500
DEADLINE: April 1, 2013
CONTACT:

Elizabeth Nash Foundation Scholarship
P. O. Box 1260
Los Gatos, CA 95031-1260
Email: webmaster@elizabethnashfoundation.org
scholarships@elizabethnashfoundation.org
info@elizabethnashfoundation.org

WEBSITE: http://elizabethnashfoundation.org/index.html

Exercise for Life Athletic Scholarship

ABOUT THE SCHOLARSHIP:
Doctors and CF centers have made it clear: when it comes to CF, exercise saves lives. BEF's Exercise for Life Scholarship is awarded annually to high school senior scholar-athletes on the basis of demonstrated financial need, academic accomplishment and athletic ability in the area of running. BEF grants one female and one male each a $10,000 scholarship. Grants are made directly to the academic institution to assist in covering the cost of tuition and fees.

REQUIREMENTS:
Applicants must be a high school senior who has cystic fibrosis and demonstrates scholastic ability, athletic ability (as evidenced by regular exercise), character, leadership, service to the community, need for financial assistance, and daily compliance to CF therapy. The student-athlete should jog on a regular basis and be training for the 1.5-mile qualifying run. All candidates will be judged on the basis of time.

- Application
- Completed Exercise For Life training log (download below)
- One-page, single-spaced essay on the importance of exercise and compliance
- Recent photo
- Letter from physician (on letterhead) confirming CF diagnosis and therapy routine
- Most recent W2 form for both parents
- Transcript (high school, college and/or graduation school)
- Letter of acceptance from academic institution
- Detailed breakdown of tuition costs from academic institution
- Signed waiver

AMOUNT: $10,000
DEADLINE: June 26, 2013
CONTACT:

Boomer Esiason Foundation
c/o Jerry Cahill
483 10th Avenue, Suite 300
New York, NY 10018
Email: jcahill@esiason.org

WEBSITE: http://esiason.org/thriving-with-cf/scholarships/exercise-for-life-athletic-scholarship.php

Gunnar Esiason Scholarship Fund

ABOUT THE SCHOLARSHIP:
With Gunnar Esiason and his sister, Sydney, both attending Boston College, the Boomer Esiason Foundation in January 2012 established a new scholarship to support the studies of a BC student. The scholarship is awarded annually.

REQUIREMENTS:
To be eligible for the Gunnar Esiason Scholarship, a student must have cystic fibrosis or have an immediate family member with CF. He or she also must already be admitted or enrolled at Boston College and qualify for financial aid by demonstrating financial need, as determined by the University's Office of Financial Aid.

- Application
- Essay
- Recent photo
- Letter from physician (on letterhead) confirming CF diagnosis and therapy routine (for the student or the student's family member with CF)
- Transcript (high school, college and/or graduate school)
- Letter of acceptance from academic institution
- Detailed breakdown of tuition costs from academic institution
- W2 form for both parents

AMOUNT: $10,000
DEADLINE: March 20, 2013
CONTACT:

Boomer Esiason Foundation
c/o Jerry Cahill
483 10th Avenue, Suite 300
New York, NY 10018

Email: jcahill@esiason.org

WEBSITE: http://esiason.org/thriving-with-cf/scholarships/gunnar-esiason-scholarship-fund.php

Individual Recreation Grants

ABOUT THE SCHOLARSHIP:

The intent when approving a Recreation Grant request is to encourage activities that physically challenges both the body and the lungs.

REQUIREMENTS:

Purchase of equipment (i.e. treadmills, elliptical, etc.) is not typically funded by CFLF, although exceptions are occasionally made for extenuating circumstances. Priority is given to grant request of greater duration (i.e., 6-month gym membership or seasonal activity is more favorable than a one-week activity). The longer the period of time covered with the request, the better.

- Completed Application
- Picture of self, doing favorite activity (digital copy preferred, please e-mail to grants@cflf.org)
- Signed Contract
- Physician Form

AMOUNT: Up to $500.

DEADLINE: N/A

CONTACT:

CFLF
Attn: Grant applications
P.O. Box 1344
Burlington, VT 05402-1344
Fax: 802.877.2034
E-mail: grants@cflf.org

WEBSITE: http://www.cflf.org/content_page/individual-recreation-grants

Jennifer Leigh Soper Cystic Fibrosis Scholarship

ABOUT THE SCHOLARSHIP:

The Jennifer Leigh Soper Scholarship was established by Lee Soper, in memory of his daughter. The scholarship will award at least $500 to a college-bound student with cystic fibrosis.

REQUIREMENTS:

Write a letter of no more than two pages that tells the committee about yourself.

Suggested information to include:

- General biographical information
- Extracurricular activities, community service, or work experience for high school or college years
- Goals for your career and life
- Your academic status
- Financial need
- How you would use the scholarship.

AMOUNT: At least $500

DEADLINE: August 1

CONTACT:

Jennifer Leigh Soper Scholarship
Blue Grass Community Foundation
250 West Main Street Suite 1220
Lexington, KY 40507
Phone: 859-225-3343
Email: kbranham@bgcf.org

WEBSITE: http://bgcf.org/

Jerry Cahill You Cannot Fail Scholarship

ABOUT THE SCHOLARSHIP:

Boomer Esiason Foundation Volunteer Jerry Cahill created the You Cannot Fail program to challenge people to discover their own heroism, embrace the ups and downs of their life's journey, make a difference by sharing that journey with others, and celebrate the stories that make them unique. As a component of that program, BEF established the Jerry Cahill You Cannot Fail scholarship in 2012 to honor exceptional student-athletes with cystic fibrosis who, like Jerry, don't let the disease get in their way of living lives filled with purpose, passion, optimism and courage. These energetic young adults also understand that exercise is the key to living, breathing and succeeding with CF, so they have embraced physical activity as part of their everyday routine. The Jerry Cahill You Cannot Fail scholarship will be awarded annually – beginning in 2013 – to one male and one female student.

REQUIREMENTS:

Applicants must have cystic fibrosis and must already have completed at least one semester of undergraduate coursework. Applicants must demonstrate that they go "above and beyond" in everything they do, displaying outstanding character, leadership and service to the community. They also must be compliant to their CF therapies and engage in regular exercise as part of their effort to stay healthy. Finally, applicants must demonstrate a need for financial assistance.

- Application
- Essay
- Recent photo
- Letter from physician (on letterhead) confirming CF diagnosis and therapy routine
- Most recent W2 form for both parents
- Transcript (college and/or graduate school)
- Detailed breakdown of tuition costs from academic institution

AMOUNT: $5,000

(Grants are made directly to an academic institution to assist in covering the cost of tuition and fees.)

DEADLINE: April 18, 2013

(The application deadline marks the anniversary of Jerry's double-lung transplant.)

CONTACT:

Boomer Esiason Foundation
c/o Jerry Cahill
483 10th Avenue, Suite 300
New York, NY 10018
Email: jcahill@esiason.org

WEBSITE: http://esiason.org/thriving-with-cf/scholarships/jerry-cahill-you-cannot-fail-scholarship.php

Kevin Hendon Model of Courage Award

REQUIREMENTS:

- Sophomore, Junior or Senior standing at Murray State University
- Must have endured severe or debilitating physical condition
- Preference to diagnosed cystic fibrosis
- Letter or explanation must accompany application
- Scholarships are very competitive. If you do not follow directions or complete all requirements of the application process, you may be eliminated from the selection process.

AMOUNT: N/A

DEADLINE: January 15 (New and Current Students), June 1 (Non-traditional Students)

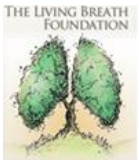
CONTACT:

Office of Financial Aid
500 Sparks Hall
Murray, KY 42071
Phone: 1-800-272-4678 Ext. 4 or 270-809-2546
Fax: 270-809-3116
Email: msu.scholarships@murraystate.edu

WEBSITE:

www.murraystate.edu/Students/Undergraduate/GettingStarted/PayingForCollege/fas/scholarships.aspx

The Living Breath Foundation Scholarship



ABOUT THE SCHOLARSHIP:

Chris and Lori Pappageorgas became involved in raising money for the Cystic Fibrosis (CF) community after both of their children were diagnosed with the disease. After only three years in operation, the Foundation already has multiple programs in place to help CF patients in need. These programs include general financial aid grants, academic scholarships, hospital care-packages, as well as helping particular individuals with very specific assistance needs.

REQUIREMENTS:

- Community involvement - list past or current community involvement (include dates/offices held)
- Extracurricular activities and interests - list (include dates and any leadership roles)
- Essay Question
- A copy of annual tuition and fees for your college/university
- A detailed list of all sources of financial aid/support already awarded (e.g. scholarships, grants work/study contributions from family, etc.)
- A photocopy of the most recent Student Aid Report (SAR), the Department of Education's response to your Free Application for Federal Student Aid (FAFSA)
- A letter of recommendation from a member of the community (e.g. teacher, employer, pastor, etc.)
- A letter from your doctor confirming a diagnosis of Cystic Fibrosis
- Incoming freshmen: An official high school transcript and a copy of acceptance letter or confirmation of enrollment from your college/university.
- For current college/university students – an official college/university transcript and confirmation of enrollment from your college/university.

AMOUNT: $500-$2,000

DEADLINE: June 1, 2013

CONTACT:

The Living Breath Foundation

2031 Marsala Cir.
Monterey, CA 93940
Phone: (831) 392-5285
Email: LivingBreathFoundation@gmail.com

WEBSITE: www.thelivingbreathfoundation.com/index.html

Loretta Morris Fund Recreation Grants

ABOUT THE SCHOLARSHIP:

In honor of her sister, Barbara and her siblings established this fund in 2010, to help CF patients share in the activities which have been enjoyed by Barbara and Loretta. Barbara was not diagnosed with CF until she was 64 years old. She is still leading an active life and regularly swimming laps. Grants are available for dance, horseback riding, golf and swimming/aquatics. Other recreation requests will be considered. California residents are given preference.

REQUIREMENTS:

Primarily intended to assist with financial access to areas of horseback riding, dance, aquatics/ swimming, or golf, request of funding for other activities will also be considered. California residents are given preference. The spirit of these funds is to help improve lifestyle; therefore preference will be given to applicants whose requests are for ongoing activities as opposed to one-time events. Applications MUST be completed by the person with CF. If a child is unable to write the parent or guardian may transcribe for them, but the words must come from the child. CFLF will only consider complete applications; this includes answering all questions and including a photo. If information is missing a letter of denial will be sent.

AMOUNT: Up to $500

DEADLINE: N/A

CONTACT:

CFLF
Attn: Grant applications
P.O. Box 1344
Burlington, VT 05402-1344
Fax: 802.877.2034
E-mail: grants@cflf.org

WEBSITE: http://www.cflf.org/content_page/loretta-morris-fund-recreation-grants

Mentor Recreation Grants

ABOUT THE SCHOLARSHIP:

The intent of a Recreation Mentor is to establish an adult support person who can provide help with facilitation of activities, companionship, support, guidance and goal setting, as well as assisting with transportation on the activities. Recreation Mentors are not a 'personal coach or physical trainer'. Instead, acting as a 'CF Coach', a Recreation Mentor may help provide support around the issues that people with CF face on an everyday basis as well as being a source of motivation and encouragement.

REQUIREMENTS:

Mentors must be at least 25 years old. Ideally, mentors should have an established familiarity with the individual (if a familiar person is not available as a mentor, CFLF will work with outside to recruit a reliable and safe volunteer). Mentors are expected to commit four hours per month of doing activities with the grant recipient.

- Completed Application
- Picture of self, doing favorite activity (digital copy preferred, please e-mail to grants@cflf.org)

- Signed Contract
- Physician Form

AMOUNT: Up to $500 is added to each grant to help cover the associated costs of a mentor participating in cost-related activities with the recipient.

DEADLINE: N/A

CONTACT:

CFLF
Attn: Grant applications
P.O. Box 1344
Burlington, VT 05402-1344
Fax: 802.877.2034
E-mail: grants@cflf.org

WEBSITE: http://www.cflf.org/content_page/mentor-recreation-grants

Peer Support Recreation Grants

ABOUT THE SCHOLARSHIP:

Our intent with this Recreation Grant option is to allow recipients the opportunity to include a friend in their activity of choice. We feel that by offering a partnership in the recreation grant activity that there is often more excitement and motivation, thus creating positive feelings toward staying active.

REQUIREMENTS:

A Peer Support is a less formal companion that participates in activities with the applicant. Because the grant is offering to cover recreation expenses for both the recipient and a peer, it will be expected that the "Peer Support" person be involved for the duration of the activity. We ask that the applicant invite a person they would like to be their peer support person FIRST, before listing them as such.

- Completed Application
- Picture of self, doing favorite activity (digital copy preferred, please e-mail to grants@cflf.org)
- Signed Contract
- Physician Form

AMOUNT: Up to $500 may be added to the grant to cover the costs for this person. If applying for a grant with peer support, the maximum dollar amount may not exceed $1,000, ($500 for the applicant and $500 for the peer).

DEADLINE: N/A

CONTACT:

CFLF
Attn: Grant applications
P.O. Box 1344
Burlington, VT 05402-1344
Fax: 802.877.2034
E-mail: grants@cflf.org

WEBSITE: http://www.cflf.org/content_page/peer-support-grants

Rimington Trophy Scholarship

ABOUT THE SCHOLARSHIP:

The Boomer Esiason Foundation established the Rimington Trophy Scholarship in 2012 to recognize individuals who are living, breathing and succeeding with cystic

fibrosis. The scholarship was established in association with the Rimington Trophy, the college football award named in honor of BEF President and former University of Nebraska center Dave Rimington.

REQUIREMENTS:

Applicants must have cystic fibrosis and demonstrate scholastic ability, character, leadership, service to the community, need for financial assistance and daily compliance to CF therapy.

- Application
- Essay
- Recent photo
- Letter from physician (on letterhead) confirming CF diagnosis and therapy routine
- Transcript (high school, college and/or graduate school)
- Letter of acceptance from academic institution
- Detailed breakdown of tuition costs from academic institution
- W2 form for both parents

AMOUNT: $1,000 to $2,000

DEADLINE: June 26, 2013

CONTACT:

Boomer Esiason Foundation
c/o Jerry Cahill
483 10th Avenue, Suite 300
New York, NY 10018
Email: jcahill@esiason.org

WEBSITE:

- http://esiason.org/thriving-with-cf/scholarships/rimington-trophy-scholarship.php
- www.rimingtontrophy.com

Rosemary Quigley Memorial Scholarship

ABOUT THE SCHOLARSHIP:

Rosemary passed away in 2004 at the age of 33. In her memory, Rosemary's husband, family, friends and colleagues established this scholarship program to enable and inspire young adults with cystic fibrosis to engage in academic studies that will lead them to lives and careers of personal and professional fulfillment.

REQUIREMENTS:

Scholarships are available to students with cystic fibrosis who are pursuing undergraduate or graduate degrees with a clear sense of life goals, and whose commitment to living life to the fullest – despite having CF – is exemplary. The scholarship committee will select finalists who will be interviewed on the phone. The award recipient will be chosen based on a majority vote based on ALL parts of the application.

- Application
- Essay
- Recent photo
- Letter from physician (on letterhead) confirming CF diagnosis and therapy routine
- Transcript (high school, college and/or graduate school)
- Letter of acceptance from academic institution
- Detailed breakdown of tuition costs from academic institution
- W2 form for both parents

AMOUNT: $500 to $2,000
DEADLINE: June 21, 2013
CONTACT:

Boomer Esiason Foundation
c/o Jerry Cahill
483 10th Avenue, Suite 300
New York, NY 10018
Email: jcahill@esiason.org

WEBSITE: http://esiason.org/thriving-with-cf/scholarships/rosemary-quigley-memorial-scholarship.php

Sacks for CF Scholarship

ABOUT THE SCHOLARSHIP:
The Sacks for CF Scholarship is related to quarterback sacks made during the NFL season. The undergraduate and graduate award is made annually to 30 people who strive for therapy adherence and academic success.

"Sacks for CF" means money in the bank for college students who have cystic fibrosis.
For every sack recorded during NFL Monday Night Football games, the Sacks for CF Scholarship Program receives a donation from a Boomer Esiason Foundation corporate partner. Sacks for CF funds are awarded annually to 30 college students, based on their academic achievements and adherence to daily CF therapy.

REQUIREMENTS:
Applications and all documentation must be received by Friday, January 11, 2013. The names of scholarship winners will be announced on Super Bowl Sunday, February 3, 2013.

- Application
- Essay
- Recent photo
- Letter from physician (on letterhead) confirming CF diagnosis and therapy routine
- Transcript (high school, college and/or graduate school)
- Letter of acceptance from academic institution
- Detailed breakdown of tuition costs from academic institution
- W2 form for both parents

AMOUNT: $3,000 to $10,000
DEADLINE: Friday, January 11, 2013
CONTACT:

Boomer Esiason Foundation
c/o Jerry Cahill
483 10th Avenue, Suite 300
New York, NY 10018
Email: jcahill@esiason.org

WEBSITE: http://esiason.org/thriving-with-cf/scholarships/sacks-for-cf-scholarship.php

Scholarship of the Arts

ABOUT THE SCHOLARSHIP:
Calling all CF artists! BEF's Scholarship of the Arts is an annual award promoting communication through creativity. Artwork in the form of video, painting, sketching and

sculpturing is considered.

REQUIREMENTS:

The CF artist must complete an application, including all documentation.

- Application
- Essay
- Recent photo
- Letter from physician (on letterhead) confirming CF diagnosis and therapy routine
- Transcript (high school, college and/or graduate school)
- Letter of acceptance from academic institution
- Detailed breakdown of tuition costs from academic institution
- W2 form for both parents
- One or more photos of art entry

AMOUNT: $500 to $1,000

DEADLINE: May 24, 2013

CONTACT:

Boomer Esiason Foundation
c/o Jerry Cahill
483 10th Avenue, Suite 300
New York, NY 10018
Email: jcahill@esiason.org

WEBSITE: http://esiason.org/thriving-with-cf/scholarships/scholarship-of-the-arts.php

Susanna Delaurentis Memorial Scholarships

THE SUSANNA DELAURENTIS CHARITABLE FOUNDATION

ABOUT THE SCHOLARSHIP:

The Susanna DeLaurentis Memorial Scholarships are awarded each year to college-bound high school seniors with superior academic and extracurricular achievements who contend with a chronic disease or other serious challenge to physical or mental health.

REQUIREMENTS:

Applicants must submit a brief statement of their health condition, how they have managed to excel notwithstanding the condition, and their plans for advanced education after high school. As much information as possible about the applicant's academic standing and achievements – including GPA, standardized test scores, and class standing – and about the applicant's participation in extracurricular or community activities should be submitted with the applicant's statement, along with at least one letter of recommendation from a member of the faculty or administration familiar with the applicant and his or her condition.

AMOUNT: N/A

DEADLINE: April 13, 2013

CONTACT:

SDCF
P.O. Box 11208
Elkins Park, PA 19027
Phone: (215) 635-9405
Fax: (215) 635-9406
Email: info@thesusannafoundation.org

WEBSITE: http://thesusannafoundation.org/

John Buller Scholarship

GREATER HOUSTON COMMUNITY FOUNDATION
Smart giving. Better results.

ABOUT THE SCHOLARSHIP

This scholarship was established by Jim and Katie Buller in 1997 in memory of their son to be used for educational grants to individuals with cystic fibrosis.

REQUIREMENTS:

Texas residents with cystic fibrosis who are undergraduate or graduate degree candidates of an accredited two or four-year college or university located in Texas and who are United States citizens.

AMOUNT: not less than $1,000 per year

DEADLINE: March 22, 2013.

CONTACT:

ISTS
855-670-4787
contactus@applyISTS.com

WEBSITE: http://www.ghcf.org/Recieve/Scholarships/John-Buller-Scholarship/

Other Resources

For other options, contact the George Washington University HEATH Resource Center for a publication entitled, "Creating Options: Financial Aid for Students with Disabilities," which provides contact information and background about financial assistance opportunities. To obtain a copy, please contact:

The George Washington University HEATH Resource Center
2121 K Street, NW, Suite 220
Washington, D.C. 20037
Phone: (202) 973-0904
Fax: (202) 994-3365
E-mail: askheath@gwu.edu
www.heath.gwu.edu

Federal Student Aid Information Center at the U.S. Department of Education provides a publication entitled "The Student Guide" which lists many financial assistance programs:

Federal Student Aid Information Center
P.O. Box 84
Washington, DC 20044-0084
Phone: (800) 4-FED-AID (1-800-433-3243)
www.studentaid.ed.gov

SOCIAL MEDIA

Personal contact between two CF patients can present problems because face-to-face meetings carry the risk of passing dangerous bacteria to each other.

However, the 21st century has made it possible *(and popular)* to communicate with friends digitally. From Facebook and email, to texting and video chatting, technology and social media provide seemingly unlimited options for CF patients to connect with each other worldwide.

Developers are constantly creating new programs, increasing the ways people with cystic fibrosis can participate, interact, and remain closely connected without risking their health.

Foundation Care welcomes your thoughts and ideas on how the CF community can stay engaged with and remain connected. Please send your suggestions to: help@foundcare.com

A **blog** is a website with regular entries commonly organized in a reverse chronological order.

Non-Profits and Other Organizations

65_RedRoses	http://65redroses.com/blog/
About.Com Cystic Fibrosis	http://cysticfibrosis.about.com/b/
Blooming Rose Foundation	www.bloomingrosefoundation.org/founders-thoughts/blog
Breathe 4 Tomorrow	http://breathe4tomorrow.org/author/breathe4tomorrow/
CF Roundtable	http://www.cfroundtable.com/
Claire's Place Foundation, Inc.	http://clairesplacefoundation.org/blog/
Cystic Fibrosis Trust	http://cftrust.blogspot.com/
Cystic Life	http://www.cysticlife.org/Blogs.php
CysticFibrosis.com	www.cysticfibrosis.com/
Foundation Care Pharmacy	www.foundcare.com/news/blog
Roadmap to CF	http://roadmaptocf.org/category/blog/

Miscellaneous Cystic Fibrosis Bloggers

100% Chance of Change	http://hundredpercentchanceofchange.wordpress.com/
2nd Chance @ life?	http://kirstie-2ndchanceatlife.blogspot.com/
66 Roses	http://66roses.blogspot.com/
a breath of fresh air...	http://abreathoffreshair-ekg.blogspot.com/
A Cyster's Life	http://beeschislifeandlungs.blogspot.com/
A Cyster's Story	http://rachelmroy.blogspot.com/
A Matter of Life and Breath	http://amatteroflifeandbreath.blogspot.com/
All my little thoughts....	http://moggymushroom.blogspot.com/
Ashlee n' Jordin's Anjels~	http://jordinlyn.blogspot.com/
being cindy {baldwin}	http://beingcindy.blogspot.com/
Bella's Blog	http://bellace85.wordpress.com/about/
Bennett Brinson Gamel	http://bennettgamel.blogspot.com/
Blue-Eyed Breather	http://blue-eyedbreather.blogspot.com/
breath to blog: one breath at a time	http://breathtoblog.blogspot.com/
Breath. Love. Justice.	http://breathlovejustice.blogspot.com/
Breathing Deeply, Laughing Loudly, and Living Fully	http://themurrayhome.blogspot.com/
Building. Essential. Breaths.	http://incomudroxcf.blogspot.com/
CF Family	http://northerncffamily.blogspot.com/
CF Stinks	http://www.cfstinks.com/
Cheriz.org	http://lifeofcheriz.blogspot.com/
Confessions of a CF Husband	http://cfhusband.blogspot.com/
Confessions of a Cyster	http://confessionscyster.blogspot.com/
Cystic Canadian	http://cysticcanadian.blogspot.com/
Cystic Fibrosis Fatboy	http://www.cffatboy.com/
Cystic Fibrosis: We're Learning as We Go	http://ourcfstory.blogspot.com/
Cysticfibrosismom	http://cysticfibrosismom.com/

Enjoy a healthy and long life with Cystic Fibrosis (CF)	http://cfandhealthy.blogspot.com/
Felix and Victor	http://felixandvictor.blogspot.com/
Fighting Fish	http://www.gofightingfish.com/index.html
From A to Pink	http://fromatopink.wordpress.com/
Hattitude	http://hattitude-hattitude.blogspot.com/
Heading For Home	http://headingfortoddhome.blogspot.com/
I have CF, but it will never have me!	http://thedriveat35.blogspot.com/
I Have CF. So what?!	http://ihavecfsowhat.blogspot.com/
Illness Inspired Words	http://illnessinspiredwords.blogspot.com/
Inhaling Hope	http://hopefulwithcf.blogspot.com/
Inspire; to breathe	http://suzannebrandsen.wordpress.com/
I've got 65 roses and they all have thorns	http://65rosesandtheyallhavethorns.blogspot.com/
Kalydeco & Ich	http://kalydecoforgermany.blogspot.com/
kris·tin·ol·o·gy - Kristin Petersen's Blog	http://www.kristinology.com/
Laughter is the Best Medicine	http://laughingmedicine91.blogspot.com/
Live* Laugh *Love* Breathe*	http://howilivelaughlovewithcf.blogspot.com/
Live. Laugh. Love. Breathe.	http://briannelh.blogspot.com/
Living the Life of an O2 Junkie	http://livingthelifeofano2junkie.blogspot.com/
Love to Breathe	http://lovetobreathe.blogspot.com/
Lungs Behaving Badly.	http://lungsbehavingbadly.blogspot.com/
Make Every Breath Count	http://nathansfight.com/
Miracles Happen	http://emileepehrson.blogspot.com/
My CF Blog	http://marcicfblog.blogspot.com/
My Journey with Cystic Fibrosis	http://mycfjourney.blogspot.com/
My Life as a Livingston	http://adamandjennylivingston.blogspot.com/
My Life with CF	http://ihavecf.blogspot.com/
My Roaring Twenties	http://justsomethinglikeit.blogspot.com/
My Running Journey with Cystic Fibrosis	http://sabrinawalkerfightscysticfibrosis.blogspot.com/
Nancy's Lung Transplant Journey	http://nancymatthews.blogspot.com/
No Two Snowflakes Are Alike	http://seeingsnowflakes.blogspot.com/
NoExcuses	http://noexcusesnoexcuses.blogspot.com/
Not Enough Oxygen	http://notenoughoxygen.blogspot.com/
Not so bright and shiny	http://notsobrightandshiny.blogspot.com/
On Eagles Wings	http://oneagleswings4ever.blogspot.com/
One Breath at a Time -- Living with Cystic Fibrosis	http://kayla-onebreath.blogspot.com/
one little drop	http://www.ruthvdb.com/
Port, Pills & Parties	http://portpillsandparties.blogspot.com/
Run Sick boy Run	www.runsickboyrun.blogspot.com
SASsy CASTLE	http://sassycastle.blogspot.com/
shine: a story of becoming found	http://becomingfound.blogspot.com/
Sister Fibrosis: Our Family's Journey with Cystic Fibrosis	http://sisterfibrosis.com/
squeegee25	http://squeegee25.livejournal.com
Stratton Family Blog	http://jimmylinastratton.blogspot.com/
The CF Diet	http://thecfdiet.blogspot.com/
The CF Ninja	http://thecfninja.com/
The Climb	http://thecfclimb.blogspot.com/

The Fight To Inhale	http://fight2inhale.blogspot.com/
The Journey of Faith	http://heleadsus.wordpress.com/
The Soderborgs	http://christinesoderborg.blogspot.com/
the story of a boy	http://cfboy.blogspot.com/
The Unknown Cystic	http://unknowncystic.wordpress.com/
TheraPink | The Pink Perspective on my life with Cystic Fibrosis	http://therapink.wordpress.com/
This is me; little Julie Jean	http://littleluellen1985.blogspot.com/
Treating Cystic Fibrosis Naturally	http://insidecf.blogspot.com/
Two Salty Boys	http://twosaltyboys.blogspot.com/
Tylers Mountain Magic	http://cysticfibrosisblog.com/
Welcome to Joshland	http://www.welcometojoshland.com/
Who Cares? LLC	http://whocaresllc.blogspot.com/
Within Deep Brown Eyes	http://withindeepbrowneyes.blogspot.com/

**This is neither a comprehensive list nor an endorsement of these organizations and bloggers. Blogs are created and deleted every day. If you write a blog or follow one regularly that relates to cystic fibrosis and would be a good addition to this list, please send the information to:*

help@foundcare.com

ONLINE COMMUNITIES

An **online community** is a group of people who communicate with one another over the Internet, usually with a common interest.

CF Voice
www.cfvoice.com/index.jsp

An online community for people of all ages living with cystic fibrosis. A place for motivation, inspiration and connection to the CF community.

CF Living
www.cfliving.com/

A community and resource for people living with cystic fibrosis (CF).

CF2Chat
www.cf2chat.com/

A community for Cystic Fibrosis patients, and those who care about them.

Club CF
http://esiason.org/thriving-with-cf/club-cf.php

There are few online venues where people with CF actually can tell their own stories and feel as if they are making real connections with other CFers. Club Cystic Fibrosis bridges this gap -- it's a web site that allows people with CF to open up and share some very personal stories with others who may be able to relate to their experiences.

CysticFibrosis.com
www.cysticfibrosis.com

CysticFibrosis.com is a social health community, founded in 1996 at the dawn of the Internet and the rise of the e-patient — the electronic or empowered patient. We are a source of information, hope, and encouragement for patients and families affected by CF. We educate each other in comprehensive and innovative ways: forums, chats, videos, newsletters, polls and blogs.

CysticLife
www.cysticlife.org

CysticLife.org is a social network just for the cystic fibrosis community. This positive, uplifting web site is the central location for the CF community to share tips, questions, ideas, experiences and encouragement. Members can maintain a profile, post blogs, ask and answer questions, directly contact one another, and search for others within the community by location, relation to CF, age and gender.

Cystic Fibrosis Connect
www.cysticfibrosisconnect.com/

Cystic Fibrosis Connect is a social network that empowers people living with cystic fibrosis. We make it easy to start conversations, share treatments, read and post product recommendations, and much more.

Daily Strength
www.dailystrength.org

Most everyone has a serious personal challenge themselves or has someone close to them that does. DailyStrength is a collection of safe, anonymous, online support groups focused on over 500 specific challenges to help people overcome their personal challenge or support a loved one through theirs. DailyStrength isn't just for those living with a challenge themselves - care givers, supporters and medical professionals are welcome as well. Everyone can use a helping hand once in a while and our mission is to provide a safe forum where people can connect with others who know exactly what they're going through.

ONLINE COMMUNITIES

eHealth Forum
http://ehealthforum.com/

eHealth Forum is an online health community that attracts 4,800,000+ unique monthly visitors. The site hosts 200+ medical forums that generate user-based health information. The site is an interactive, 100% professionally moderated social network; our administrative staff reviews every post.

HealingWell.com
www.healingwell.com/cysticfibrosis/

HealingWell.com is about living mindfully and healing well with chronic illness. It is a community where people come together, reach out, find support and understanding, and share what works for them with others. HealingWell.com features a thriving support community, blog, videos, a popular newsletter, articles and resources to help you actively manage the challenges of living with chronic illness. The goal is simple....to help you take control of your illness and start "healing well".

Inspire
www.inspire.com

Inspire builds online health and wellness communities for patients and caregivers, in partnership with national patient advocacy organizations, and helps life science organizations connect with these highly engaged populations.

MDJunction
www.mdjunction.com/

MDJunction is a meeting place for people who deal with health challenges, a comfort zone to help and get help by people who are in your spot. Founded in 2006 MDJunction is now home to more than 800 online support groups visited by more than 16,000,000 people in the past year.

Medpedia
www.medpedia.com/communities/198-Cystic-Fibrosis

Join this community to have conversations with knowledgeable people and get real-time updates. For medical professionals, caregivers, scientists, researchers, advocates, public health professionals, and those interested in learning more about Cystic Fibrosis and related conditions.

PatientsLikeMe
www.patientslikeme.com/patients

PatientsLikeMe is a for-profit company, but not one with a “just for profit” mission. We follow four core values: putting patients first, promoting transparency (“no surprises”), fostering openness and creating “wow.” We’re guided by these values as we continually enhance our platform, where patients can share and learn from real-world, outcome-based health data. We’ve also centered our business around these values by aligning patient and industry interests through data-sharing partnerships. We work with trusted nonprofit, research and industry Partners who use this health data to improve products, services and care for patients.

Sharktank
www.sharktank.org

Sharktank Research was formed in 1998 to find a cure for cystic fibrosis through extensive research, critical analysis, and the exchange of ideas. The members of the group either have cystic fibrosis or have children with it.

**This is neither a comprehensive list nor an endorsement of these organizations and individuals. If you host an online community or follow one regularly that relates to cystic fibrosis and would be a good addition to this list, please send the information to:*

help@foundcare.com

FACEBOOK

Facebook is a social networking service launched in February 2004. As of September 2012, Facebook has over one billion active users, more than half of whom use Facebook on a mobile device. Users must register before using the site, after which they may create a personal profile, add other users as friends, and exchange messages, including automatic notifications when they update their profile. Additionally, users may join common-interest user groups, organized by workplace, school or college, or other characteristics, and categorize their friends into lists such as "People From Work" or "Close Friends".
Information provided by http://en.wikipedia.org/wiki/Facebook

News and Organizations

65_RedRoses #4Eva /65redrosesfilm	Join Us! http://www.65RedRoses.com/ 65_RedRoses is an award-winning film about Eva Markvoort which has evolved into the #4Eva movement for organ donation and cystic fibrosis awareness. Join Us! www.65RedRoses.com
Blooming Rose Foundation /Blooming-Rose-Foundation	The Blooming Rose Foundations' mission is to positively assist individuals and families who have a diagnosis of Cystic Fibrosis through support, advocacy and referral services.
Bonnell Foundation: Living with cystic fibrosis /thebonnellfoundation	The purpose of The Bonnell Foundation is to provide tools to navigate the difficulties of living with CF. We strive to connect families with resources through their CF journey. With our website, roadmap to CF baskets, medical and academic scholarships we hope to equip families with a roadmap to guide their way.
Boomer Esiason Foundation /BoomerEsiasonFoundation	Boomer Esiason Foundation Staff, fighting Cystic Fibrosis, CF scholarships, transplant grants, podcast, charity-non profit.
Build4Life Cystic Fibrosis /Build4Life	Build4Life/Cystic Fibrosis aim is to develop adult and paediatric Cystic Fibrosis services including both outpatient and inpatient facilities within Cork University Hospital. As we come closer to providing these life saving facilities we will then provide funding for the needs of the Cystic Fibrosis departments including staff, research and any other needs that they may have.
CF Roundtable /CFRoundtable	CF Roundtable is a newsletter for adults with CF, published by USACFA. http://www.cfroundtable.com/ The purpose of USACFA is to provide a source of information for CF adults regarding the basis, nature and progression of the disease, as well as the latest treatments and research to fight it. It also offers a forum for CF adults to communicate with each other.
CFRI /cfri.org	Cystic Fibrosis Research, Inc. (CFRI) is a 501(c)(3) nonprofit organization that funds CF research, provides educational and personal support, and spreads awareness of cystic fibrosis.
CFvoice.com /CFvoice	Welcome to CFvoice! Novartis isn't responsible for content on the CFvoice Friend Activity tab or content shared by Facebook users. This content is not endorsed by Novartis. CFvoice is a place for motivation, inspiration and connection to the cystic fibrosis community - proudly brought to you by Novartis Pharmaceuticals Corporation.
Claire's Place Foundation, Inc. /Claires-Place-Foundation-Inc	Our mission is to heighten public awareness about Cystic Fibrosis, and improve the quality of life for the families it affects by providing education, life skills, inspiration, and positive support.
Cody Dieruf Benefit Foundation /The-Cody-Dieruf-Benefit-Foundation	The Cody Dieruf Benefit Foundation was formed in March of 2006 in honor of Cody Dieruf who passed away from Cystic Fibrosis at 23 years old. Our mission is to help financially our community families, scholarships for educ/cultural.
Cystic Fibrosis Canada /CysticFibrosisCanada	National health charity working to help Canadians with cystic fibrosis live longer, healthier lives! The Cystic Fibrosis Canada Facebook Page is an online community where people can share information, tell their story, and interact with one another.
Cystic Fibrosis Foundation /cysticfibrosisfoundation	Advancing the search for a cure for cystic fibrosis by funding research, promoting awareness and providing support to patients and families.

Cystic Fibrosis Lifestyle Foundation /CFLifestyle	CFLF assists in providing avenues toward healthy and active lifestyles through recreation, thereby educating people with Cystic Fibrosis on the critical psychological, social and emotional connections between their lifestyle and their health.
Cystic Fibrosis Trust /cftrust	The Cystic Fibrosis Trust is the UK's only national charity dealing with all aspects of Cystic Fibrosis (CF). This page provides a platform for supporters to come together, to share their experiences and to communicate.
Cystic Fibrosis Worldwide /Cystic-Fibrosis-Worldwide	CF Worldwide is an international organization comprised of over 65 member countries from around the world. Our mission is to act as a platform for the exchange of information about cystic fibrosis globally. It is the goal of CFW to develop programs that will aid in research, spreading education and bringing the international CF community together.
CysticFibrosis.com /knowcf	CysticFibrosis.com is a social health community, founded in 1996 at the dawn of the Internet and the rise of the e-patient — the electronic or empowered patient. We are a source of information, hope, and encouragement for patients and families affected by CF. We educate each other in comprehensive and innovative ways: forums, chats, videos, newsletters, polls and blogs.
CysticLife /cysticlife	Serving the cystic fibrosis community while working to spread awareness and find a cure. Fulfilling our mission online first with our recently launched www.CysticLife.org - The Social Network for the Cystic Fibrosis Community. Check it out!!
Foundation Care Pharmacy /FoundationCarePharmacy	A full-service, retail pharmacy providing customized patient care and personalized service from a professional staff. Our main focus is quality, respect, and commitment to care.
Jerry Cahill /jerry.cahill1	Motivational Speaker/CF Ambassador · New York, NY Motivational Speaker/CF Ambassador CF @ Boomer Esiason Foundation. Team Boomer Founder, Oversee Educational Programs & Transplant Grants, scholarships, CF podcasts, CLUB CF, CF Wind Sprints, and YOU CANNOT FAIL.
Mauli Ola Foundation /MauliOlaFoundation	The Mauli Ola Foundation (MOF) was organized to promote education, awareness of genetic diseases and to increase research for genetic disorders. The MOF raises funds to support programs for kids and adults with life-threatening illnesses and disabilities through social events such as music concerts, sports tournaments, galas, and other great events. We want to provide a direct and immediate option for children with genetic disorders to experience an enjoyable and healthy way of life through natural treatments.
Rock CF Foundation /Rock-CF-Foundation	The Rock CF Foundation is a 501(c)3 nonprofit corporation. Founded and led by Emily Schaller, the Rock CF Foundation is dedicated to increasing the quality of life for people with Cystic Fibrosis. With the help of a core group of volunteers, the Foundation utilizes the arts, entertainment, fashion and fitness to support research initiatives and heighten public awareness in the fight against cystic fibrosis.
Welcome to Joshland: The Blog & The YouTube Channel /w2joshland	This is a page where you - my readers/watchers - and I - the writer, video maker, nerdy, child-like goofball - can connect. I've left this page open for you to post comments, pictures, and videos on the wall. Let's keep them happy, uplifting, and appropriate for kids to read. Be respectful: keep the comments clean and the media fun!

**This is neither a comprehensive list nor an endorsement of these organizations and individuals. Facebook pages are created and deleted every day. If you manage a Facebook page or follow one regularly that relates to cystic fibrosis and would be a good addition to this list, please send the information to:*

help@foundcare.com

PHONE APPLICATIONS

A **cell phone app**, sometimes called a mobile app, is any cell phone application, particularly those that are directly purchased and installed by phone users. These are smartphone add-ons that perform functions other than making a phone call, ranging from games to medical monitoring. To term "app" can be used to refer to any application for any device, but when used alone, it most commonly refers to software downloaded onto cell phones.
**Definition provided by: www.wisegeek.org*

Blausen Respiratory Atlas — **$4.99**

The Blausen Human Atlas iPhone application provides point-of-care access to 3D animations of common medical treatments and conditions, (approximately 1-2 minutes in length) with accompanying narration. Derived from the world's largest award winning medical animation library, this digital resource tool has no equal in quality and quantity of animation, scientific accuracy and ease of use.

CF GeneE by Vertex — **FREE**

CF GeneE is an educational app for healthcare professionals that work on your iPhone. Use CF GeneE as a resource to view information about common mutations in the CFTR (cystic fibrosis transmembrane conductance regulator) gene that lead to cystic fibrosis disease.

CFI - Cystic Fibrosis Ireland — **FREE**

This App will enable the Cystic Fibrosis Ireland (CFI) to create more awareness of Cystic Fibrosis to both our own members and the wider community. Through the provision of latest news updates, information can be relayed to members in real-time. This will also be important from an advocacy perspective and in times when national campaigns are ongoing. The CFI also has a wide variety of grant and support services (e.g., exercise/fertility grant) available for members and some of these schemes are managed by specific deadlines. The CFI App will enable us to alert members when specific schemes are open and also to remind them about forthcoming deadline. This Application will also be hugely beneficial from a Fundraising perspective as it will enable us to alert members to national and community events going on around the country.

Chest PT — **FREE**

This app allows you to set total positions, minutes per position and a rest period between positions (we know how tiring your wrist can get). It will also alert you when it's time to change positions.
- It's free and has no ads.
- It's built exclusively to serve as a timer for cystic fibrosis patients. It doesn't contain all the unnecessary features that complicate most other interval timers.
- Includes a "good job" screen when all positions completed to reward your child. This can also be customized with your child's name.
- Doesn't feature a big countdown clock that seems to cause time to crawl. Simple graphic that is a little more fun to watch.
- Customize the sound used to indicate the end of each position.
- Choose to include a rest period between positions, this would also give you time to move your child into a new position.
- Set up daily reminders to alert you to begin your child's manual chest physical therapy.
- Simple and intuitive interface just in case you have your hands full with your child.

PHONE APPLICATIONS

Cure CF by the Cystic Fibrosis Foundation — **FREE**

Download this app and learn more about CF, what the organization is doing to help cure this disease, connect with them on Facebook, watch inspirational video and send messages to your friends about what they can do to help and support this great cause. The mission of the Cystic Fibrosis Foundation, a nonprofit donor-supported organization, is to assure the development of the means to cure and control cystic fibrosis and to improve the quality of life for those with the disease.

Cystic Fibrosis Connect by Alliance Health Networks, Inc — **FREE**

Get connected with a large growing community of people living with cystic fibrosis. With Cystic Fibrosis Connect mobile, you can follow discussions while on the go, ask your questions and add comments to interesting posts. It's the place to discuss treatments, start conversations, and learn from others. Cystic Fibrosis Connect empowers people living with cystic fibrosis through sharing experiences and creating a community of support.

Cystic Fibrosis Forum by ML Burke Consulting Inc (CysticFibrosis.com) — **FREE**

Welcome to the community for people concerned with cystic fibrosis. With our cystic fibrosis forum mobile application you will be able to do the following:

1. Send and receive PM's
2. Access post to the most recent discussions
3. Read and post blogs

Flower Breath — **FREE**

Many young people suffering from respiratory problems must perform daily physiotherapy with a Flutter medical device. The Flutter ® VRP1 is a kind of plastic pipe fitted with a metal ball, which set in motion by the breath of the patient, produces vibrations that loosen the mucus. Children with CF (Cystic fibrosis) are required to perform these exercises for at least 5 minutes 2-3 times each day. For young patients and their caregivers, these are tedious and discouraging exercises. Researchers have looked for ways to introduce visual feedback and game dynamics into these exercises in order to increase their effectiveness and make the therapy less monotonous. The idea is to make these exercises, still practiced at home, more playful and to improve the quality of breathing exercises.

Inhaler Counter — **$0.99**

An incredible app for keeping track of ALL your inhalers dosage. Whether you use your inhaler on a prescribed schedule or on an as needed bases, Inhaler Counter will make keeping track of your Inhaler's doses easy.

Jerry Cahill's CF Wind Sprints — **$1.99**

Now enjoy Jerry Cahill's CF wind Sprints, presented by the Boomer Esiasion Foundation (BEF), right from your phone. With this app you get an inside look at how Cahill maintains a healthy and active lifestyle and answers questions from viewers like you! Twitter, star your favorites and Facebook included!

PHONE APPLICATIONS

Jerry Cahill's Cystic Fibrosis — $1.99

Now enjoy Jerry Cahill's Cystic Fibrosis Podcast, presented by the Boomer Esiason Foundation (BEF), right from your iPhone, iPad or iPod Touch. BEF is a non-profit organization dedicated to funding research for CF and improving the quality of life of those affected by cystic fibrosis. Jerry Cahill is a 52-year-old male with CF who has been able to thrive with a disease that has an average lifespan of 31 years. In this podcast Jerry gives his views on living with CF. This App features:

- Streaming access to play episode from anywhere
- Always updated with the latest episodes- and an archived back catalog
- Download the episodes and play them when offline
- Playback resume (when interrupted by a call or other distraction)
- Favorites (mark the episodes you want to return back to over and over)

Muck Busters! By Genentech — FREE

Utilize the unique abilities of this colorful team of characters to help you get rid of sticky slime and enemies. The game also includes a way to help keep track of your day if you have CF.

RT: For Decision Makers in Respiratory Care — FREE

RT: For Decision Makers in Respiratory Care is a leading source of information for respiratory care practitioners; providing clinical information, updates on trends, practical insights, business tips, and news on the latest product and services.

SpiroSmart — *Not Yet Available*

SpiroSmart is a mobile phone based platform that allows for the analysis of common lung function measures (FEV1, FVC, PEF). By analyzing lip reverberation we are capable of monitoring pulmonary ailments such as asthma, chronic obstructive pulmonary disease, and cystic fibrosis. To increase compliance, our target monitoring platform is the mobile phone, a sufficiently small device that is always with the patient. Additionally, we are investigating methods to make the lung testing procedure part of a simple, yet engaging, game on the phone.

TCPal™ CF Treatment Tracker by Novartis — FREE

Organize, schedule and track your daily cystic fibrosis treatment regimen right on your iPhone or iPod Touch. Its easy-to-use tool to help manage daily treatments, medication, nutrition, and exercise – and it's free. Easily enter you full treatment regimen in just a few steps. Add therapies, medications, exercise and calories with all the details including any additional instructions from your health care professional. Schedule the time and frequency for each of your daily treatments, and then see your day's schedule hour by hour. To help you keep up with your treatments, TCPal™ will send a discreet reminder for your scheduled treatments right from your iPhone/iPod Touch. You'll also receive alerts if you're missing too many treatments. Get a comprehensive view of how you're doing. Track your progress by the day, week, month, and year for your treatments, exercise, calories, and FEV1.

PHONE APPLICATIONS

Wishing Star — $0.99

With this photo app, you can conjure a shooting star in the evening sky at all times and make a wish - either for yourself or for your friends. Lufthansa has made this app which enables you to make a wish at all times. All you need to do is create a shooting star, make a wish for yourself or someone else and then really believe in it. Wherever you might be - simply draw a shooting star on the camera image with your finger. You can either save the resulting photo in your gallery or send it to friends with a personal wish. Inspired by the greatest wish for a cure for cystic fibrosis.

CF-specific mobile apps are helpful for cystic fibrosis patients, *but what about the rest of the family?*

Below are just two examples of the *hundreds* of compliance and adherence applications available on mobile devices. We suggest you always check the ratings and reviews before downloading and purchasing a mobile app.

RxmindMe — FREE

RxmindMe is a prescription reminder that uses multitasking to alert you every time you need to take a prescription. We allow you to enter all your prescriptions, setup reminders, and track when you have taken them.
Features include:

- Nine types of reminders
- Prescription quantity tracker
- Export prescription data
- Take pictures of your prescriptions
- Email prescription history
- Family members for medications
- Entire FDA Drug Database
- Secure!

Tonic — $2.99

Winner of “Best Mobile Health Solution for Behavior Change” at the Mobile Health 2011: What Really Works! conference held at Stanford University. Tonic is the first caregiving app that fully supports both you and your family’s self care efforts. It helps you remember and keep track of everything in your health regimen, making it easier to take care of yourself and everyone else in your family. It’s simple and easy to use, and well attuned to the messy complexity of real-world, day-to-day health. Features include:

- Flexible reminder schedules
- Local notifications
- Flexible event entries
- Event log
- Easy sharing of your health regimen (to your caregivers)

PODCASTS

A **podcast** is an audio or video program formatted to be played on the iPod and made available for free or for purchase over the Internet. Podcasts are shows, similar to radio or TV shows, which are produced by professionals or amateurs and posted to the Internet for download and listening or viewing. Many podcasts are made available for free, though some must be purchased. The name derives from the combination of broadcast and iPod.
**Definition found at: http://ipod.about.com/od/itunes/g/podcast_define.htm*

CFLiving
http://www.cfliving.com/resources/webcasts.jsp

Videos and webcasts to get helpful information on living with CF. New videos are added regularly.

CFRI*live*!™
http://www.cfri.org/CFRIlive.shtml

CFRI broadcasts presentations online LIVE to give viewers like you the opportunity to ask questions from home.

CFvoice.com Podcasting Network
www.cfvoice.com/info/caregivers/podcasts/index.jsp

Meet other families living with CF on the CFvoice.com Podcasting Network. Our line-up includes parents, grandparents, siblings and spouses sharing what it's like to love and care for someone with cystic fibrosis. Subscribe to the CFvoice podcast RSS feed today and get the bi-weekly audio casts delivered to your computer.

Cystic Fibrosis Connect
www.cysticfibrosisconnect.com/videos

Links to videos on a variety of topics relating to cystic fibrosis.

Cystic Fibrosis Foundation
www.cff.org/LivingWithCF/Webcasts/

Produced by the Cystic Fibrosis Foundation, this innovative series of webcasts brings the cystic fibrosis community together in a "Virtual CF Education Day" forum to learn from the experts about living with CF and the latest in CF research. Each webcast features different members of the CF healthcare team, or experts in CF research, from across the United States.

Cystic Fibrosis Worldwide
www.cfww.org/podcasts/ | itunes.apple.com/us/podcast/cystic-fibrosis-worldwide/id410030824

Podcasts of Cystic Fibrosis Conferences and Meetings

eCysticFibrosis Review
https://itunes.apple.com/us/podcast/cystic-fibrosis-review/id300355725

Timely commentary on current research, best practices and clinical management issues, provided by an expert panel of Cystic Fibrosis Specialists.

Great Ormond Street Hospital for Children

Listen to young peoples' amazing stories about their experiences at Great Ormond Street Hospital (GOSH).

- Cystic Fibrosis Teens — www.gosh.nhs.uk/teenagers/real-stories/podcasts/cystic-fibrosis/
- Lung Function Test — www.gosh.nhs.uk/teenagers/real-stories/podcasts-tests-and-treatments/lung-function-test/
- Physio for CF — www.gosh.nhs.uk/teenagers/real-stories/podcasts-tests-and-treatments/physio-for-cystic-fibrosis/

PODCASTS

Healthcare 411: News Series from AHRQ (Agency for Healthcare Research and Quality)

http://healthcare411.ahrq.gov/radiocastseg.aspx?id=1152&type=seg

This audio program features current news and information from the U.S. Agency for Healthcare Research and Quality (AHRQ). A new AHRQ report shows using a medicine called human growth hormone may relieve some symptoms of Cystic Fibrosis.

Jerry Cahill's Cystic Fibrosis Podcast

http://jerrycahill.com/

With the help of today's therapies, CF patients are living longer and achieving more than ever before, and an increasing number of adults with CF are pursuing their dreams by attending college, entering the working world and raising families. Their stories serve as the basis for a popular series of podcasts and vodcasts produced by BEF Volunteer Jerry Cahill. The "Living. Breathing. Succeeding." series of podcasts, made possible by an unrestricted educational grant from Genentech, provides information and inspiration to the CF community and anyone else who's interested in CF.

Joshland

www.welcometojoshland.com/p/joshland-podcast.html

A CF podcast that gets inside the heads of the CF Community to talk about the all kinds of topics with respect and honesty. This podcast will feature guest panelists each episode and will include topics such as:

- The 3 Foot Rule
- The ups and downs of Social Media
- Myths and Reality of Transplant and Organ Donation
- Transitioning from a Pediatrician to an Adult Doctor
- Gender Roles
- CF Couples
- CF Parents
- Spouses of the CF Community
- Relationships and Friendships
- *And many, many more!*

It has reoccurring segments to bring a little laughter and lighten the mood after some serious discussions.

MUSC Health Audio Podcasts

www.muschealth.com/multimedia/Podcasts/searchresult.aspx?keyword=cysticfibrosis

The MUSChealth.com Podcast Library features podcasts on a variety of topics related to your health and services at MUSC. These medical podcasts are hosted by MUSC faculty, physicians and special guests and are produced and directed by Linda Austin, M.D. CF-themed podcasts include:

- Bronchiectasis: An Overview
- Cystic Fibrosis: Dietary Needs
- Infertility: Female Factor Infertility and Donor Eggs
- Sinus: Effects of Secondhand Smoke
- Cystic Fibrosis: An Overview
- Cystic Fibrosis: Transition into Adulthood
- Scleroderma: What is Scleroderma?

Special Report: New Cystic Fibrosis Drug Brings Gift Of A Future

http://commonhealth.wbur.org/2011/05/cystic-fibrosis

A still-experimental drug, called VX-770, while not a cure, is being called a "major advance" in CF research. VX-770 attacks the basic defect in cystic fibrosis, and right now helps only 4 percent of those living with cystic fibrosis. Carey Goldberg explains what VX-770 does, and how it's helped one woman do things she's never done before — like shovel snow.

**This is neither a comprehensive list nor an endorsement of these organizations and individuals. If you host a podcast or follow one regularly that relates to cystic fibrosis and would be a good addition to this list, please send the information to:*

help@foundcare.com

TWITTER

Twitter is a real-time information network that connects you to the latest stories, ideas, opinions and news about what you find interesting. Simply find the accounts you find most compelling and follow the conversations.
At the heart of Twitter are small bursts of information called Tweets. Each Tweet is 140 characters long, but don't let the small size fool you—you can discover a lot in a little space. You can see photos, videos and conversations directly in Tweets to get the whole story at a glance, and all in one place.

CF News and Organizations

65_RedRoses @65_RedRoses	*Eva Markvoort's struggle with #cysticfibrosis while on wait list for a lung transplant. Official Selection of Oprah Winfrey Network DOC club. Join the movement*
Battle of the Badges @CFBattleBadges	*Battle of the Badges: Climb for a Cure is a stair-climbing competition in Columbus, OH that raises money and awareness for The Cystic Fibrosis Foundation*
Belle Raisers @BelleRaisers	*Official Twitter feed for Belle Raisers Cystic Fibrosis Foundation Great Strides national team. Until CF means Cure Found, we will Continue Fighting! North Carolina, USA*
@CysticFibro_bio	*The BioPortfolio Twitter feed for the latest news, reports, research papers and clinical trials on Cystic Fibrosis - Serving the Life-Science Industry.*
Blooming Rose Foundation @Blooming65roses	*The Blooming Rose gives hope following a diagnosis of cystic fibrosis. The BRF offers an online resource & links to positive websites and blogs.*
Bonnell Foundation @RoadmapToCF	*The purpose of The Bonnell Foundation: Living with cystic fibrosis is to provide tools for parents (funds, education, resources) to navigate a life with CF.*
Boomer Esiason Foundation @cysticfibrosis	*Boomer Esiason Foundation Staff, fighting Cystic Fibrosis, CF scholarships, transplant grants, podcast, charity-non profit.*
CF at SCHOOL @CFatSCHOOL	*Dedicated to providing information and resources that assist in the management of Cystic Fibrosis (CF) at School. Brisbane, Qld, AU ·*
CF Aware @CFAware	*Raising awareness using Cystic Fibrosis facts. Please always refer to your CF Team for specialist advice. #cfaware http://www.cfaware.co.uk*
CF Foundation @CF_Foundation	*Advancing the search for a cure for cystic fibrosis by funding research, promoting awareness and providing support to patients and families.*
@CFFoundationLA	*CF is a life threatening genetic disease that affects the lungs and digestive system of more than 30,000 Americans. The average life expectancy is 37.8 years!*
CF Trust @cftrust	*The Cystic Fibrosis Trust is the UK's only national charity dealing with all aspects of Cystic Fibrosis (CF).*
CFF - GNYC @CFF_GNYC	*Official twitter for the Cystic Fibrosis Foundation Greater New York Chapter! ~Manhattan, Long Island & Westchester~*
CFF's YPLC in NYC @CFFYoungProsNYC	*We are a team of dynamic young professionals in NYC, who are committed to raising money and awareness for Cystic Fibrosis. Join us!*
CFLF @CFLifestyle	*Helping people with Cystic Fibrosis with Recreation Grants toward Living Stronger! & Living Longer!*
@CFResearch	*Updating those who are interested in the latest Cystic Fibrosis news and research*

CFRI @CysticFibrosisR	*Cystic Fibrosis Research, Inc. (CFRI) is a 501(c)(3) nonprofit organization, founded in 1975. CFRI's mission is to fund research, provide educational and personal support, and to spread awareness of cystic fibrosis, a life-threatening genetic disease.*
CFRoundtable @CFRoundtable	*A Newsletter for Adults who have CF: Providing Support, Information and Encouragement Since 1990*
CFWorldwide @CFWorldwide	*CFW is an international non-profit aiding people with CF globally. www.cfww.org for more info!*
Coach-Ed.org @CFCoachEd	*Coach-Ed is a charity whose mission is to engage & support patients living with #CysticFibrosis & their families to live beyond the limitations of #CF.*
@CF_65roses	*are you a carrier? help raise awareness and hopefully find a cure*
Cystic Fibrosis @CFadvisorygroup	*A way to connect KU Med patients & their families w/ CF to Doctors & others in the community who are fighting CF. Ask ?'s, receive updates! Fight for a Cure!*
Cystic Fibrosis @CFFNebraska	*Nebraska*
Cystic Fibrosis @iCysticFibrosis	*Cystic Fibrosis is a lung disease that causes mucus to build up on the lungs and pancreas for more info visit*
@GrandChefsGala	*The 16th Annual Grand Chefs Gala/Jean Banchet Awards will bring together Chicago's top chefs at the Fairmont on Feb 8, 2013 to benefit the CF Fdn.*
@GreatStridesChi	*The Cystic Fibrosis Fdn is hosting 14 Great Strides Walks throughout Chicagoland during April and May. Go to the website above to register for a walk near you.*
@CFinAustralia	*Our Aim: facilitate and promote the provision of optimal care to all people affected by Cystic Fibrosis and ensure they have the best possible quality of life.*
Cystic Fibrosis Kids @CF_Kids	*We provide equipment 4 kids with CF in Portsmouth that are essential for their daily routine, but may not be available on the NHS budget. Reg Charity No.1115580*
Cystic Fibrosis LI @CFHuntLI	*"The Hunt" will be followed by a celebration at 300 Long Island, honoring the Finest traditions, landmarks, companies & individuals on Long Island.*
Cystic Fibrosis NSW @CFNSW	*We support people with cystic fibrosis (CF) and their families in NSW through services, lobbying and contribution to research.* *Sydney, NSW · http://www.cysticfibrosis.org.au/nsw/*
Cystic Fibrosis QLD @CysticFibrosis_	*Queensland · http://www.cfqld.org.au*
@CFSouthAus	*Cystic Fibrosis SA is a not for profit organisation which provides information and support services for people with Cystic Fibrosis living in South Australia.*
Cystic Fibrosis TO @CF_Toronto	*Cystic Fibrosis Canada - Toronto & District Chapter works to help Canadians with cystic fibrosis live longer, healthier lives*
@CysticFibrosisV	*CFV is a not-for-profit charitable organisation who provide advocacy, support and information services to people with CF and their families.*
@CysticFibrosis1	*Our mission is to contribute to the social, physical and emotional well being of those affected by cystic fibrosis and to assist in the promotion of research.*
CysticFibrosisCanada @CFC	*National health charity working to help Canadians with cystic fibrosis live longer, healthier lives!*

CysticFibrosisDiag @CysticFibrosisD	*Cystic fibrosis, mucoviscidosis, mukoviszidose, sweat test, fibrosis* *http://www.cysticfibrosisdiag.com*
CysticLife @CysticLife	*Serving the Cystic Fibrosis community*
EmsEntourage4CF @EmsEntourage4CF	*Emily's Entourage is about joining together and leveraging the power of community to make a difference in the fight against Cystic Fibrosis.*
Foundation Care Pharmacy @FoundationCare	*Specialty (Respiratory/Diabetes) Pharmacy - Retail & Compounding Pharmacy - Reimbursement Specialists - 2011 BBB TORCH Award Winner*
Friends For Life @FFLFoundation	*Uniting friends in the fight against Cystic Fibrosis and Cancer. Toronto ·* *http://www.fflf.ca*
Great Strides @CF_GreatStrides	*Cystic Fibrosis Foundation's largest fundraising event with 600 walks nationwide where thousands come together to raise money to help find a cure for CF.*
KalydecoBot @KalydecoBot	*Provides info on Kalydeco. Kalydeco is used to treat patients with #cysticfibrosis aged over 6 years who have a G551D mutation in the CFTR gene.*
@KnowCF	*Welcome to the community for people concerned with cystic fibrosis. Visit our interactive forums and blogs to find support and share information.*
Make CF History @MakeCFHistory	*Raising $1 million for the Cystic Fibrosis Foundation: An annual hockey tourney for men, women, and kids, silent/live auction, and more -- June 7-9th, 2013!*
Mauli Ola Foundation @MauliOlaSurf	*The Mauli Ola Foundation (MOF) exists to introduce surfing as a natural treatment to people with genetic disorders. #CoolDudeTour*
MNT Cystic Fibrosis @mnt_cysticfibro	*The latest cystic fibrosis news published daily. Articles from research centers, universities and prestigious journals.*
SharktankCF @sharktankCF	*http://www.sharktank.org*

People who Post about Cystic Fibrosis

Aaron Rogers @aaronrogers1975	*I'm 37, I have Cystic Fibrosis, am an Independent Beachbody coach, and a single dad. My mission is to help people get in shape, eat right, and stay healthy!*
Adam: theCFninja.com @CF_Ninja	*I have #cysticfibrosis ΔF508, but still a #ToughMudder. A healthy lifestyle is key, so love life, have some self control, exercise & be water. Go Noles!*
Amity Furr ❤ @amitydawn	*23. Engaged. living with Cystic Fibrosis. Happy with my life! Huge Casey James & Keith Urban fan! http://www.giveforward.com/amitysfightagainstcf*
Andy Lipman @AndyLipman1	*Husband to Andrea. Dad to Avery and Ethan. Enemy to cystic fibrosis. #curecf!* *http://www.andylipman.com*
Bianca Nicholas @BiancaNicholas	*Just a girl who ♥'s to sing! Released top 100 single on iTunes & Amazon in Oct 2011 No.1 on Vocal Chart. Yes, I have #CysticFibrosis - but it doesn't have me! X*
Bradley Howington @Brad_Howington	*Hello, I'm Bradley. 23. Poet, writer, photographer, activist and cystic fibrosis advocate. ♥ photography, music and writing.*
Caley Camarillo @MissCaley	*latest update on my site. please support me & cystic fibrosis research!*
CF Fatboy @cffatboy	*A 30-something dude with cystic fibrosis on a journey to gain weight to reach 23 BMI. Mission accomplished!*

CFAwareness @CFAwareness	*Father of a 5 yr old with DD F508.Spreading awareness,sharing support,looking forward to a cure for #cysticfibrosis.*
CFMama @CFMama	*Christian wife and mom, cystic fibrosis advocate, breastfeeding, co-sleeping, cloth diapering, babywearing, natural childbirth & photography enthusiast.*
Cystic Fibrosis @UnknownCystic	*Everything I say is a lie. USA · http://unknowncystic.wordpress.com/*
Cystic Fibrosis teen @Cysticteenlife	*I'm a 16 year old girl with Cystic Fibrosis, my aim is to contact other people with CF:) I follow back!*
@cysticbot	*I retweet mentions of Cystic Fibrosis*
@Help_CF	*Everyone Deserves A Better Quality Of Life xx*
jerry cahill @jcahillYCF	*CF Podcasts, CF Wind Sprints, Living Breathing Succeeding with CF, Running, Exercise for Life, Boomer Esiason Foundation volunteer, YOU CANNOT FAIL...*
@jbenj219	*27 yrs old w/Cystic Fibrosis. Had a double lung transplant on 7/22/12! Love Dogs, Rootbeer, Survivor, and Gravy. Respect is earned not given. Love My Tucker*
Josh from Joshland @w2joshland	*I do the best I can every day. I love my family and friends. Oh yeah, & I have cystic fibrosis. Check out http://www.mogankoforcf.org for the Moganko CF Project*
@KatharineS84	*freelance writer/editor. CF patient & advocate. lover of social media. denison alum. grammar marm. book hoarder.*
@MaciDrewry	*I am 10 and have cf, i love life and love being a cheerleader! Davis Cleveland helps me teach people about cf. Mason Cook helps too. Pray for a cure everyday!*
Oli Rayner @oli_rayner	*Writer and biogeek with Cystic Fibrosis. I also own and run @Kalydeco. Former investment banker and VC. This ain't no dress rehearsal. My views. Plymouth/London*
Punk! vs. Fibrosis @punkvsfibrosis	*Proceeds from our shows are sent to various Cystic Fibrosis foundations.*
@CheekyRob	*I'm 21 & have Cystic Fibrosis, G551D, 20% FEV1, Supplemental Oxygen. I love my two Miniature LH Dachshunds, they keeps me fighting CF. I follow back :-)*
@BobCoughlin	*President and CEO of @MassBio. Patient Advocate and proud father of a 10 year old boy with Cystic Fibrosis. #curecf #biotech #cysticfibrosis*
RockCFem @RockCFem	*Breathe Deep. Run Hard. Rock CF. I run, ride & rock to raise awareness and funds to help make CF stand for Cure Found.*
Ronnie Sharpe @RunSickboyRun	*I tweet about what's important to me: family, god, cystic fibrosis, social networking, blogging, exercise, running, medicine, business and random facts.*
Sarah Tucker @jtuck123	*Mum to 3 boys one with Cystic Fibrosis a lifethreatening genetic condition. Here to raise awareness and support for Cystic Fibrosis Trust.*
@SaveBigDave	*Living with Cystic Fibrosis and raising Cystic Fibrosis awareness.*
Sharon Brennan @SharonBrennan	*Writer and journalist living in London and living with Cystic Fibrosis. Check out my blog - latest news and opinions on NHS.*

Tim Wotton @timwotton	*Husband to Katie & father to Felix, comms manager in London, sport lover with CF - blogging about my experiences to raise awareness*
@Tor87	*24 year old musical theatre fan. Cystic Fibrosis sufferer, waited 4years for a double lung transplant and finally recieved the gift of life 10.10.11!*

**This is neither a comprehensive list nor an endorsement of these organizations and individuals. Twitter accounts are created and deleted every day. If you manage a Twitter account or follow one regularly that relates to cystic fibrosis and would be a good addition to this list, please send the information to:*

help@foundcare.com

LOCAL RESOURCES

This page was created to help you keep track of your local health-related resources we haven't mentioned that you utilize regularly; this way, everything you need to know is in one place!

LOCAL RESOURCES

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GLOSSARY

A

ABSORB/ABSORPTION: The passage of substances into or across tissues, such as the passage of food and water from the intestines into the bloodstream. Because of a lack of digestive enzymes, some foods eaten by people with CF may not be well absorbed and used by the body (see DIGESTIVE SYSTEM, ENZYMES, PANCREAS, INTESTINE and MALABSORPTION).

ADVERSE REACTION: Unwanted side effect resulting from a drug or mixture of drugs. It may appear quickly or over time (see SIDE EFFECTS).

AEROSOLIZED: A liquid substance released as a spray.

AIRWAYS: Tubes that bring outside air into the lungs. The lungs have many airways of varied sizes. The largest is the trachea between the throat and the lungs. It branches into smaller airways in the lungs called bronchi. These divide into still smaller branches called bronchioles. These turn into alveoli, the very smallest airways.

AIRWAY CLEARANCE TECHNIQUES (ACTS): Different methods to loosen thick, sticky mucus in the lungs. Examples include coughing, huffing (forcefully pushing air out through the mouth), chest physical therapy, high-frequency chest wall oscillation, intrapulmonary percussive ventilation, oscillating positive expiratory pressure, percussion, and positive expiratory pressure therapy.

ALVEOLI: A tiny, thin-walled, capillary rich sac in the lungs where exchange of oxygen and carbon dioxide takes place. Singular: Alveolus.

AMINOGLYCOSIDES: A group of antibiotics used to treat bacterial infections. Tobramycin and gentamicin are examples of aminoglycosides used in CF treatment (see ANTIBIOTIC and BACTERIA).

ANTIBIOTIC: A drug that kills bacteria or slows bacterial growth. Antibiotics are often used to treat lung infections (see AMINOGLYCOSIDES, BACTERIA and CEPHALOSPORINS).

ANTI-INFLAMMATORY AGENT: Medication to reduce inflammation or irritation of body tissue. Ibuprofen is an example of an anti-inflammatory agent used in CF treatment.

ANTIBODY: molecule in the body that combines with a foreign bacteria or virus to stop its activity or signal other molecules in the body to become active in fighting the foreign germ.

ANTIMICROBIAL: Can stop the growth of disease-causing germs.

APPROVED DRUG: In the United States, only drugs approved by the Food and Drug Administration (FDA) can be sold. The approval process involves several steps, including pre-clinical laboratory and animal studies, clinical trials for safety and effectiveness, filing a New Drug Application by the drug manufacturer, FDA review and approval of the application (see FOOD AND DRUG ADMINISTRATION).

ARM: Any of the treatment groups in a randomized trial. Most randomized trials have two arms, but some have three or more (see RANDOMIZED TRIAL).

ASSAY: A way to measure how many parts of a certain ingredient are in a larger system, object or mixture.

AUTOSOMAL RECESSIVE: A genetic trait or disorder that appears only when a person inherits a pair of chromosomes, each of which has the gene for the trait. One chromosome of the pair comes from the father and the other from the mother. Autosomal recessive disorders occur only if each parent is either a carrier of the trait or has the trait. CF is an autosomal recessive disease (see CARRIER and GENE).

B

BACTERIA: Tiny one-celled creatures that are often the cause of infections. People with CF are prone to bacterial lung infections (often caused by the bacteria Staphylococcus aureus and Pseudomonas aeruginosa). Some bacteria normally found in the body are helpful. For example, Escherichia coli live in the intestines and help with digestion (see ANTIBIOTIC, INTESTINE, *PSEUDOMONAS AERUGINOSA* and STAPHYLOCOCCUS AUREUS).

BALANCED STUDY: When a particular type of participant (for instance, females, people with certain lung function levels, African Americans, etc.) is equally represented in each study group.

BIAS: A point of view that impairs fair judgment. In clinical trials, bias is controlled by blinding and randomization (see BLIND TRIAL and RANDOMIZATION).

BIOFILM: A substance that sticks to wet surfaces. Biofilms can form on solid or liquid surfaces as well as on soft tissue in living organisms. They are usually difficult to dissolve. In CF, a biofilm, or protective coating, is formed by *Pseudomonas aeruginosa* bacteria and prevents drugs from killing the bacteria.

BIOMARKERS: A biochemical or a substance in the body that can be used to measure disease activity or effects of treatment.

BILE: A bitter fluid produced by the liver and stored in the gallbladder. Bile is discharged into the small intestine when needed to aid in the digestion of fats.

BILIARY FIBROSIS: A disease of the gallbladder, bile ducts, and bile characterized by the replacement of normal tissue with fibrous tissue and loss of functional cells.

BLIND TRIAL: A clinical trial in which participants are unaware whether they are taking the experimental drug, placebo or standard treatment. (see SINGLE BLIND TRIAL and DOUBLE BLIND TRIAL).

BMI (Body Mass Index): A measurement comparing fat to muscle in the human body. Weight in kilograms is divided by height in meters to figure out the degree of nutritional health, such as determining malnutrition or obesity.

BROAD SPECTRUM: An antibiotic that is effective against a wide range of organisms.

BRONCHO-ALVEOLAR FLUID: Fluid found in the bronchiole and alveoli part of the lungs.

BRONCHO-ALVEOLAR LAVAGE: A diagnostic test where fluid is taken from the bronchioles and alveoli part of the lungs.

BRONCHOSCOPY: A procedure using a small tube (bronchoscope) to look down the throat and inside the lungs.

BRONCHUS: The large airways that move air from the trachea to the lungs. The bronchi (more than one bronchus) branch into smaller airways called bronchioles. These lead to the alveoli. In CF, mucus can clog the bronchi and interfere with breathing.

BURKHOLDERIA CEPACIA COMPLEX: Bacteria that can live in the lungs of people with CF and cause infection. This bacterium is resistant to antibiotics and easily spread between people with CF, and can cause life-threatening lung infections.

C

CADAVERIC: Having to do with a dead body (a cadaver).

CARRIER: A person having a single gene for a genetic trait or disorder like CF. Carriers show no signs of the disease. In CF, each parent of a child with CF either has CF or is a CF carrier (see GENE and HEREDITARY).

CELL: The basic unit of living organisms.

CEPHALOSPORINS: A group of antibiotics used to treat bacterial infections (see ANTIBIOTIC and BACTERIA).

CFTR: see CYSTIC FIBROSIS CONDUCTANCE TRANSMEMBRANE REGULATOR

CHROMOSOME: The thread-like material that carriers genes, the units of heredity. Chromosomes are in the nucleus of every living cell. Every person should have 23 pairs of chromosomes in each cell.

CHRONIC: A disease or condition that lasts and is continuous. CF is a chronic disease.

CILIA: Small, hair-like projections on the outer layer of some cells, including many of those in the bronchial epithelium.

CIRRHOSIS: A chronic disease of the liver characterized by the replacement of normal tissue with fibrous tissue and the loss of functional liver cells.

GLOSSARY

CLINICAL: Related to the study and treatment of people in a medical setting or clinic.

CLINICAL ASSESSMENT: An evaluation of the symptoms and progression of a disease.

CLINICAL INVESTIGATOR: A medical researcher, most often a medical doctor, responsible for carrying out a clinical research protocol (see PROTOCOL and PRINCIPAL INVESTIGATOR).

CLINICAL STUDY: A type of research—also called observational research—in which participants are observed. While these studies do not use drugs or treatments, they are very important for developing new ideas about how diseases or progression of disease could be prevented or treated.

CLINICAL TRIAL: A type of research—also called interventional research—that follows certain government guidelines for testing the effect of drugs on people. Researchers observe how the drug affects the body under highly controlled conditions and whether the treatment is helpful.

CLINICALLY STABLE: When symptoms are not changing or progressing and, for the time being, are not expected to.

COMPASSIONATE USE: When experimental drugs are provided to people before final FDA approval. Typically used only with individuals who may receive benefit but have no other treatment options and cannot enroll in a clinical trial.

COMPLEX DOSAGE REQUIREMENTS: When clinical trial participants are required to take an experimental drug or treatment several times a day or to take a combination of drugs and treatments.

COMPUTED TOMOGRAPHY (CT scan): A three-dimensional image or picture of the body showing three measurements, such as height, width and depth. Created by a computer from a series of cross-sectional pictures.

CONDENSATE: Something that has turned into liquid, such as a liquid reduced from a gas or vapor, like water from steam.

CONFIDENTIALITY: The FDA and medical ethics require that the identities and medical information of all clinical trial participants be kept confidential. When a person joins a clinical trial, they must agree to share their medical records with researchers. The Principal Investigator must guarantee these records remain confidential (see FDA and PRINCIPAL INVESTIGATOR).

CONTRAINDICATED: Used to describe when certain medicines or treatments should not be used.

CONTROL GROUP: In many clinical trials, one group of patients receives the experimental drug or treatment, while the control group receives either a standard treatment or placebo (see PLACEBO and STANDARD TREATMENT).

CONVENTIONAL: Following what is traditional or customary. Not new or experimental.

CULTURE: Sputum or throat swab is put on a medium for germs to grow in the laboratory, so the germ can be identified.

CYSTIC FIBROSIS CONDUCTANCE TRANSMEMBRANE REGULATOR (CFTR): A protein in the cell that makes the channel where chloride moves in and out. The defect in the channel causes CF.

CYSTIC FIBROSIS-RELATED DIABETES (CFRD): The body's inability to move sugar from the blood into the cells for energy. A special form of diabetes found in people with CF.

D

DATA SAFETY MONITORING BOARD (DSMB): An independent committee of clinical research experts and community representatives that reviews ongoing information from a clinical trial. The committee's job is to watch for safety issues and ensure participants are not exposed to unnecessary risk. The DSMB can recommend that a trial be stopped.

DEFICIENCY: A lack of something necessary to good health. An insufficiency. Example: a Vitamin D deficiency in people with CF.

DEHYDRATED: Remove moisture.

DEOXYRIBONUCLEIC ACID (DNA): The chemical coding for a gene. DNA decides the "genetic message" in each cell, organ, and organism.

DETECT: To discover the existence, presence, or fact of. To uncover something that has been hidden or is not as it should be.

DETERIORATION: The process of becoming worse. Example: when someone's health deteriorates.

DIAGNOSE: To find the cause of health problems.

DIGESTION: The process of breaking down the food we eat and absorbing its nutrients into the body for energy (see ABSORPTION).

DIGESTIVE SYSTEM: The organs that take in, digest and get rid of food. Includes the mouth, salivary glands, pharynx (throat), esophagus, stomach, intestines, liver, pancreas, colon, rectum and anus. In CF, thick mucus blocks some passages in the digestive system, like that between the pancreas and intestines.

DOSAGE: The prescribed amount of a drug that must be taken to get the benefit or intended result.

DOUBLE BLIND TRIAL: A clinical trial in which neither the participants nor the staff knows which patients are receiving the experimental drug and which are receiving a placebo or standard therapy. Double blind trials are thought to be more objective because expectations of the physician and the participants don't affect the outcomes (see BLIND TRIAL, SINGLE BLIND TRIAL and PLACEBO).

DRUG-DRUG INTERACTION: Changes in the effect of a drug when taken with another drug. The effect may be an increase or a decrease in the action of either drug, or it may be an adverse effect normally not associated with either drug (see ADVERSE REACTION).

DSMB: See DATA SAFETY MONITORING BOARD.

DUCT: A tube or passageway for secretions. Ducts are found in organs, such as the pancreas, organ systems and exocrine glands. In CF, thick mucus can block these ducts (see SECRETION).

E

EFFICACY: The ability of a drug to produce a desired effect. A drug will pass efficacy trials if it is effective at the dose tested against the illness for which it was prescribed.

ELIGIBILITY CRITERIA: Reasons for selection of participants to be excluded from a clinical trial (see INCLUSION/EXCLUSION CRITERIA).

ENERGY INTAKE: Energy helps cells perform all of their functions, including building proteins and other substances the body may require. Energy intake is based on food that is eaten.

ENROLL: Joining a clinical trial, after meeting all necessary criteria and signing the Informed Consent Form (see INCLUSION/EXCLUSION CRITERIA and INFORMED CONSENT DOCUMENT).

ENZYMES: Proteins that help make and increase certain chemical processes in the body, like the breaking down of foods in digestion. Because people with CF have mucus that often blocks the passageways (or ducts) through which digestive enzymes from the pancreas flow, they may need enzyme replacements to digest food (see ABSORPTION, DIGESTIVE SYSTEM, MUCUS and PANCREAS).

ESOPHAGUS: The tube that leads from the throat (pharynx) to the stomach.

EXACERBATION: Signs and symptoms that show a need for treatment.

EXCLUSION/INCLUSION CRITERIA: Standards used to decide whether a person may or may not enroll in a clinical trial. Criteria are based on such factors as age, gender, disease, previous treatment history, and other medical conditions. These criteria are not used to keep people out of clinical trials, but rather to identify the right participants and keep them safe in a trial.

EXHALATION: Breath out air.

EXPANDED ACCESS: Refers to any of the FDA procedures for distributing experimental drugs to patients who are no longer benefiting from currently available treatments and unable to participate in ongoing clinical trials (see COMPASSIONATE USE, PARALLEL TRACK and TREATMENT IND).

EXPERIMENTAL DRUG: A drug not licensed by the FDA for use in humans (see OFF-LABEL USE).

F

FDA: See FOOD AND DRUG ADMINISTRATION.

FAILURE TO THRIVE: Not gaining weight or growing at a normal rate.

FOOD AND DRUG ADMINISTRATION (FDA): The agency of the U.S. Department of Health and Human Services (DHHS) responsible for monitoring the safety and effectiveness of all drugs, biologics, vaccines and medical devices, including those used in the diagnosis, treatment and prevention of CF and other diseases (see http://www.fda.gov/).

FORCED EXPIRATORY TECHNIQUE (FET): A strong expiration made by contracting the abdominal muscles while keeping the mouth and glottis open (unlike a cough, which requires closure of the glottis), also called huff technique.

FORCED EXPIRATORY VOLUME IN ONE SECOND (FEV1): The amount of air that can be forced out in one second after taking a deep breath.

FORCED EXPIRED VITAL CAPACITY (FEVC, FVC): The largest volume of air that can be forced out rapidly after taking a deep breath.

FORMULATION: A prescribed recipe for making a drug.

G

GASTROESOPHAGEAL REFLUX DISEASE (GERD): a condition in which food or liquid travels backwards from the stomach to the esophagus (the tube from the mouth to the stomach). This action can irritate the esophagus, causing heartburn and other symptoms.

GENE: The main unit of heredity. Each chromosome carries hundreds of genes. Genes decide body traits like eye and hair color, height, facial features and many health problems. CF is caused by an alteration of a gene. A child inherits CF when two CF genes are received, one from each parent (see AUTOSOMAL RECESSIVE, CARRIER and HEREDITARY).

GENETIC: Hereditary or inherited. Material that is passed on from parents to children (see GENE).

GLAND: A group of cells that make substances so that other parts of the body can work. The pancreas is a gland that makes enzymes so food can be broken down and absorbed by the body.

GLUCOSE: A sugar.

GOOD CLINICAL PRACTICE (GCP): The standard for clinical trial design, conduct, performance, monitoring, auditing, recording, analyzing and reporting. GCP ensures that reported results will be credible and accurate, and that the rights, integrity and confidentiality of patients are protected.

GRAM NEGATIVE: Bacteria that does not retain the violet dye stained by Gram's stain method (method classifies bacteria as positive or negative).

GRAM POSITIVE: Bacteria that retain the violet dye when stained by Gram's stain method (method classifies bacteria as positive or negative).

H

HEMOGLOBIN: The oxygen-carrying protein that gives red blood cells their color.

HEREDITARY: Traits or conditions, like eye color or CF, that are genetically passed from parents to their children (see GENE and GENETIC).

HETEROZYGOUS: Having different pairs of genes for any hereditary characteristic

HIGH-RESOLUTION COMPUTER TOMOGRAPHY (CT scan): A three-dimensional image or picture of the body. Created by a computer from a series of cross-sectional pictures with edge-defining qualities to sharpen the image, sometimes with a closer view of a smaller area. A close-up CT scan. Used often to create images of a person's lungs (see COMPUTED TOMOGRAPHY).

HOMOZYGOUS: Having the same pairs of genes for any hereditary characteristic.

HORMONE: Secretion from glands. Hormones regulate body functions like growth and heart rate.

HUFF TECHNIQUE (HUFFING): A strong expiration made by contracting the abdominal muscles while keeping the mouth and glottis open (unlike a cough, which requires closure of the glottis). Also called forced expiratory technique (FET).

HYDRATING: Add moisture.

HYPERGLYCEMIA: Higher than normal blood glucose or blood sugar in the bloodstream.

HYPOTHESIS: Theory or assumption used as a guide in clinical research.

I

IND: See INVESTIGATIONAL NEW DRUG.

IRB: See INSTITUTIONAL REVIEW BOARD.

IMMUNE: Resistant to infection by a specific germ.

IMPAIRED GLUCOSE TOLERANCE: A fasting blood sugar of 100 to 125 mg/dL and /or a blood sugar of 140 to 199 mg/dL 2 hours after an oral glucose load during an oral glucose tolerance test (OGTT).

INACTIVE (Inert): Having no effect.

INCLUSION/EXCLUSION CRITERIA: Standards used to decide whether a person may or may not enroll in a clinical trial. Criteria are based on such factors as age, gender, disease, previous treatment history, and other medical conditions. These criteria are not used to keep people out of clinical trials, but rather to identify the right participants and keep them safe in a trial.

INDICATION: Something that points to or suggests the proper treatment of a disease, as required by the cause or symptoms. Like a tip-off, or clue, that certain action is required.

INDUCTANCE PLETHYSMOGRAPHY: A machine to measure lung volume and lung health in people ages 6 years of age and older. Sometimes called a "body box."

INFECTION: Infection occurs when bacteria or other organisms (for example, fungus) grow in airways and cause illness.

INFLAMMATION: The swelling of body tissues due to irritation or injury. Inflammation occurs with an infection.

INFORMED CONSENT: The process of learning about a clinical study or trial before deciding whether to join. Doctors and nurses involved in the trial fully explain the study and answer any questions. The goal is to have people participate who are informed about the study or trial.

INFORMED CONSENT DOCUMENT: A document that describes the rights of clinical research participants and details about the study or trial. It includes the study's purpose, length, required procedures, and staff contact information. It also explains any risks and potential benefits. The patient should ask the study staff any questions before signing.

INHALE: To breathe in.

INHERITED: Traits or conditions, like eye color or CF, that are genetically passed from parents to their children (see GENE and GENETIC).

IN-PATIENT (IN-PATIENT STUDY/TRIAL): Hospitalized patient. Study or trial that requires time in a hospital.

INSTITUTIONAL REVIEW BOARD (IRB): Committee of research and disease experts, and community advocates working to ensure that a clinical trial is fair and ethical, and that the rights of all participants are protected. All clinical trials in the United States must be approved by an IRB before they can begin. This group approves the initial research and reviews the research as it progresses to help protect the rights and safety of participants. The IRB also must approve all materials prepared for participants, including the informed consent document, promotional posters, flyers, brochures, Web sites, and other items.

INTERVENTIONS: Approach to treating a disease or condition. Intervention is a word frequently used to describe a treatment or therapy.

INTESTINE: Tube in the digestive system that connects the stomach to the anus. The long, narrow, upper part is the small intestine. The short, wide, lower part is the large intestine. Also called the bowel.

INTRAMUSCULAR: In the muscle. Example: a “shot” or intramuscular injection.

INTRAVENOUS (IV): Putting a medicine right into a blood vessel, usually a vein, using a thin needle and a tube.

INVESTIGATIONAL NEW DRUG (IND): An experimental drug that is approved by the FDA for use in clinical trials.

INVESTIGATIONAL TREATMENT: An unapproved treatment, or a treatment used for a new purpose in clinical research. This is usually a drug.

IN VITRO: Latin for “in glass.” Usually refers to research in a laboratory, outside the body.

IN VIVO: Latin for “in living (body).” Usually refers to research done in living animals and humans.

L

LIVING DONOR: A living person who donates a body part for transplantation into another person. Many different types of organs can come from living donors, like a kidney, or a lobe of a lung or liver.

LIVING SYSTEMS: Human, animal, or cell environments used for experimental purposes in clinical trials (see IN VITRO and IN VIVO).

LOBAR: A well-defined part of an organ or gland. The lungs have several distinct lobes.

LUNG CLEARANCE INDEX (LCI): The result (a number) obtained from a multiple breath washout test. A higher number reflects more airway obstruction and a low number a healthier lung. A patient with more obstruction will take longer to clear the gas mixture from their lung and the result is a higher number or index (see MULTIPLE BREATH WASHOUT).

LUPUS: Any of several diseases, which first affect the skin and joints, but often involve other parts of the body.

M

MACROLIDES: A group of antibiotics used to treat lung infections, including azithromycin and erythromycin.

MALABSORPTION: Poor uptake of nutrients from food for use by the body. In CF, mucus may plug ducts of digestive organs and block the secretion of enzymes and hormones. This makes many nutrients unavailable for use in body maintenance and growth (see ABSORPTION, DIGESTION, DIGESTIVE SYSTEM, DUCT, ENZYME, FAILURE TO THRIVE, HORMONE, MUCUS, ORGAN, PANCREAS and SECRETION).

MARKERS: A substance in the body that, when present in large or abnormal amounts, suggests the presence of disease. Also called a biomarker.

MICROBIOLOGY: The branch of biology that deals with microorganisms and their effects on other living organisms. The study of microscopic forms of life (such as bacteria, viruses, and fungi).

MICROORGANISMS: A form of life that can be seen under a microscope. Germs are microorganisms.

MODELS: Represents a living system and used in research.

MUCOCILIARY CLEARANCE: In the airways of the lungs, this system works to move mucus and particles breathed in to upper airways so they can be coughed out of the lungs.

MUCOID: Resembling mucus; forming large moist sticky colonies of bacteria.

MUCOLYTIC AGENTS: A group of drugs that thin secretions, making them easier to clear.

MUCOSAL: A fluid made by mucous membranes and glands. Normally thin and slippery. In CF, mucus is thick and sticky.

MUCUS: A fluid made by membranes and glands. Mucus is normally thin and slippery. In CF, the mucus is often thick and sticky (see GLAND, MUCUS MEMBRANE, PHLEGM and SPUTUM).

MUCUS MEMBRANE: Tissue that contains mucus-making glands. Mucus membranes are found in the nose, mouth, lungs, esophagus, stomach, and intestines (see ESOPHAGUS, GLAND, INTESTINE, MUCUS and TISSUE).

MULTI-CENTER: More than one medical or research institution, such as a multi-center clinical study.

MULTIPLE BREATH WASHOUT: A test of lung function technique that measures the amount of obstruction or blockage in the airways. For this test, which can be used in people of all ages, the patient inhales a special gas mixture during normal relaxed breathing. The time that it takes for gas to wash out of the lung is measured and used to calculate the lung clearance index (LCI) (see LUNG CLEARANCE INDEX).

MUTATION: A change in a gene (see AUTOSOMAL RECESSIVE, CARRIER, CHROMOSOME, GENE, GENETIC, HEREDITARY and INHERITED).

N

NSAIDS: Non Steroidal Anti-Inflammatory Drugs, such as ibuprofen and aspirin (see ANTI-INFLAMMATORY AGENT).

NATIONAL INSTITUTES OF HEALTH (NIH): The agency of the U.S. Department of Health and Human Services (DHHS) responsible for health and medical research. NIH conducts research in its own laboratories

and funds billions of dollars in research at other facilities, including universities, in the United States and abroad.

NEBULIZER: A device that delivers a mist when attached to an air compressor.

NEUTROPHIL: A white blood cell that destroys foreign bacteria in the body.

NEW DRUG APPLICATION (NDA): An application for a new drug submitted to the FDA to review and approve an experimental drug. The application is submitted after the completion of clinical trials and before a drug can be available to the general public.

NONINVASIVE: Not penetrating the body, as by incision. Used to describe a diagnostic procedure that does not invade healthy tissue.

NOVEL TECHNIQUE: A newly used skill or procedure.

O

OBSTRUCTED: To block, make difficult to pass.

OFF-LABEL USE: When a drug is prescribed for conditions other than those approved by the FDA.

OPEN-LABEL TRIAL: A clinical trial where all parties, including physicians and participants, know if they are using an investigational drug. Also when all participants get to receive the investigational drug once its safety and effectiveness have been established and before the FDA approves it.

ORAL: Taken by mouth.

ORAL GLUCOSE TOLERANCE TEST (OGTT): This test is used to diagnose not just diabetes and CFRD but also the varied types of abnormal glucose tolerance in CF. You must first fast (nothing to eat or drink) for 12 hours. Then, blood is drawn to measure your “baseline” or “fasting” glucose level. You are then asked to drink glucose. Your blood sugar is measured again 2 hours later. Often, blood sugar is measured at 1, 2, and 3 hours later.

ORGAN: A part of the body that performs a specific function or group of functions. Some common organs are the heart, lungs, and brain. A group of related organs is an organ system, such as the digestive system.

ORGANISM: A form of life, such as a plant, animal, bacterium (single bacteria) or fungus.

ORPHAN DRUGS: An FDA category of medications used to treat rare diseases and conditions which affect fewer than 200,000 people. Orphan drug status gives a drug manufacturer a greater financial incentive to develop and provide such drugs. CF is an orphan disease.

OSCILLOMETRY: Measurement of changes, used in studying cardiovascular and respiratory functions.

OUTCOME: Overall results of a study or trial offered up for evaluation. Also called an endpoint.

OXIDANT: A substance that oxidizes another substance.

OXIDIZES: To combine with oxygen.

P

PFTs: See PULMONARY FUNCTION TESTS.

PANCREAS: A long organ with glands found behind the stomach. The pancreas secretes enzymes through ducts into the intestine to break down food. In CF, mucus may obstruct the pancreatic ducts, preventing digestion. Another part of the pancreas has endocrine tissue, which makes a hormone called insulin. Insulin controls storage and use of sugar (see ENZYMES and MUCUS).

PANCREATIC INSUFFICIENCY (PI): The failure to properly digest food due to a lack of digestive enzymes made by the pancreas.

PARALLEL TRACK TRIAL: A system of making experimental drugs available to individuals who are unable to participate in clinical trials.

PARAMETER: Used to measure the quantity or function of something. Example: FEV_1 is a measurement, or parameter, for lung function.

PEER REVIEW: Careful review of a clinical trial by experts who consider its scientific merit, participant safety and ethics.

PERCUSSION: In chest physiotherapy, a technique that includes clapping and vibrating the chest wall with one's hands.

PHARMACOKINETICS: The processes (in a living organism) of absorption, distribution, metabolism, and excretion of a drug or vaccine.

PHASE 1 TRIALS: First step in drug development to test a drug's safety and to find out how the human body reacts to the drug. The purpose of Phase 1 trials is to discover the side effects of increased doses and collect early evidence of drug effectiveness. Healthy volunteers or people who do not have the disease or condition being studied, are often included.

PHASE 2 TRIALS: Research that tests the effectiveness and safety of a new drug. Identifies common side effects and risks.

PHASE 3 TRIALS: Usually the last type of clinical trial before a drug is approved by the FDA. Intended to gather more information about 1) the general risk-benefit of the drug, and 2) how to administer the drug (see RISK-BENEFIT).

PHASE 4 TRIALS: Research conducted after FDA approval to get additional information about the drug's long-term risks, benefits, and best possible use.

PHLEGM: Mucus made from glands in the airways of the lung.

PLACEBO: A pharmaceutical preparation that contains no active substance (a sugar pill), and looks like the drug that is being tested.

PLACEBO CONTROLLED: A drug is studied by giving an inactive substance (a placebo) to one group of participants, while the drug being tested is given to another.

PLACEBO EFFECT: A change that occurs after a person takes a placebo.

PNEUMONIA: An inflammation of the lungs often caused by a bacterial or viral infection. Pneumonia is a problem in people with CF.

POLYMERASE CHAIN REACTION (PCR): A laboratory technique for quickly fusing large amounts of DNA together from a single DNA segment.

PORCINE: Of or derived from pigs.

PRECLINICAL: Testing of experimental drugs in the test tube or in animals. Occurs before clinical trials in humans are done.

PREVENTION TRIALS or STUDIES: Research to find better ways to prevent disease in people who have never had the disease or prevent disease from returning.

PRINCIPAL INVESTIGATOR (PI): Person responsible for the conduct of the clinical trial at a research site.

PROCEDURE: Something done to fix a health problem or learn more about it. For example, surgery, tests and putting in an IV (intravenous line) are procedures.

PROTEIN: Proteins are a basic part of all living cells. Found in foods such as meat, proteins are essential in the diet for growth and repair of tissue.

PROTOCOL: A detailed plan for a clinical trial. It describes what types of people may participate in the trial; the schedule of tests, procedures, medications and dosages; and the length of the study.

PSEUDOMONAS AERUGINOSA: A type of bacteria that often lives in the lungs of people with CF and causes lung infections (see ANTIBIOTIC, BACTERIA and STAPHYLOCOCCUS AUREUS).

PULMONARY: Relating to the lungs.

PULMONARY FUNCTION TESTS (PFTs): Tests to check lung function. Along with the patient's history and physical exam, PFTs help doctors diagnose a health problem, and decide what therapy to prescribe. They can be used with children five years and older. PFTs measure air flow and lung volumes.

Q

QUALITY OF LIFE: A concept that considers a person's physical, mental, and emotional health, level of independence, social relationships, personal beliefs and relationship to their environment.

R

RANDOMIZATION: Commonly used to assign clinical trial participants to a treatment arm, based on chance (see ARM).

RANDOMIZED TRIAL: Participants are assigned by chance to one of two or more treatment arms of a clinical trial (see ARM).

RECRUITMENT: Act of enrolling people in a clinical trial.

RECRUITMENT PERIOD: Time frame allowed to recruit for a clinical trial.

REPRODUCIBLE: To make a counterpart, image, or copy. To produce again or anew. To re-create. In clinical research, it refers to the ability of one study to recreate the results of a different study, thereby showing that the results are valid.

RESEARCH:

Applied Research
Studies that apply basic research findings to problems like diseases and symptoms. Examples: creating new respiratory equipment or studying cell defects in the sweat glands of people with CF (see CELL and GLAND).

Basic Science Research
Studies that increase knowledge of basic life processes. To learn the causes of CF, scientists do basic science studies like gene studies and research on how cells work (see CELL, GENE and GENETIC).

Clinical Research
Studies in people that improve diagnosis and treatment. Examples: studies on drugs, lung function, nutrition, and sweating. (see DIAGNOSE, PULMONARY FUNCTION TESTS and SWEAT TEST).

RESEARCH COORDINATOR: A staff person chosen by the principal investigator to assist him/her in conducting the clinical trial (see PRINCIPAL INVESTIGATOR).

RESISTANCE: The ability of an organism to defend itself, either from disease or from being harmed. Example: bacteria can become resistant to antibiotics and no longer be killed by the drugs.

RISK-BENEFIT RATIO: The known risk of participating in a clinical trial weighed against the potential benefits.

S

SAFETY: The condition or state of being safe. In clinical trials, this refers to an absence of harmful side effects resulting from use of the product and may be assessed by special tests and procedures, psychiatric evaluation, and/or physical examination of participants.

SAFETY PROFILE: A summary of clinical data that explains the possible side effects of a certain drug or treatment.

SCREENING: Identifying a potential clinical trial participant by finding out if the person meets the eligibility criteria (see ELIGIBILITY CRITERIA).

SCREENING STUDIES: Refers to studies that test how to identify diseases or conditions.

SECRETION: A product of a gland, like sweat or saliva (see GLAND).

SENSITIVE: Responsive to a stimulus. Easily irritated or inflamed.

SIDE EFFECTS: Any unexpected results from taking an investigational drug or treatment (see ADVERSE REACTION).

SINGLE BLIND TRIAL: A trial where either the investigator or participant is unaware of which treatment arm the participant is assigned to (see BLIND TRIAL, DOUBLE BLIND TRIAL and ARM).

SPACER DEVICE: A hollow chamber that fits on the mouthpiece of a metered dose inhaler. It makes the inhaler easier to use and more efficient in delivering medicine.

SPIROMETER: A device that measures air flow and lung volumes (see PULMONARY FUNCTION TESTS).

SPONSOR: Individual, company, institution or organization responsible for initiation, management and financing of a study.

SPUTUM: Mucus or phlegm coughed up from lungs (see MUCUS and PHLEGM).

SPUTUM CULTURE: A test to see what germs may be growing in the sputum (see SPUTUM).

SPUTUM DENSITY: A measurement of mucus or phlegm coughed up from lungs.

STANDARD TREATMENT: An effective treatment or drug approved by the FDA for a specific disease or condition.

STANDARD OF CARE: Treatment or medical management based on state-of-the-art health care (see STANDARD TREATMENT).

STAPHYLOCOCCUS AUREUS (STAPH): A type of bacteria that can cause infections. In CF, "staph" often causes lung infections. It is treated with antibiotics (see ANTIBIOTIC and BACTERIA).

STATISTICAL SIGNIFICANCE: The probability that an event or change did or did not occur by chance.

STUDY ENDPOINT: Results from a clinical trial used to judge the effectiveness of a drug treatment (see OUTCOME).

SUB-STUDY: A smaller study that is part of a larger study.

SURFACTANT: A chemical that can reduce the surface tension of a liquid in which it is dissolved so that it spreads out more easily.

SUSCEPTIBILITY: Being prone to, sensitive to, or lacking the ability to resist something.

SWEAT TEST: A test to diagnose CF. Measures the salt (sodium and chloride) in sweat.

SYSTEMIC: Affecting the body as a whole.

T

THERAPEUTIC: Refers to a substance that has a healing effect on a specific condition.

TISSUE: A group of cells of a similar type and function.

TOLERABILITY: Ability to tolerate, put up with, or endure.

TOLERABLE DOSAGE: Highest recommended amount of a substance that does not have adverse results (see ADVERSE REACTION and SIDE EFFECTS).

TOXICITY: The degree to which a drug is harmful or poisonous. A drug's toxicity will vary depending on amount and use.

TRACHEA: Also known as the windpipe, the largest central airway, the trachea connects the upper respiratory tract to the lower respiratory tract.

TRACHEOSTOMY: An opening through the neck and into the trachea, through which a tube is inserted to create an airway.

TREATMENT IND: IND stands for Investigational New Drug, and is part of the FDA's approval process to market a new prescription drug. This process makes promising investigational drugs available to patients outside of clinical trials early in the drug development process, before the FDA approves it as a new drug.

TREATMENT TRIALS: Refers to trials that test new drugs, new combinations of drugs, or new approaches to standard medical treatments.

TRIGGER: A device used to release or activate a mechanism. An event that causes other events to happen.

U

UNDUE OR UNNECESSARY RISK: IRBs review clinical trial protocols to ensure participants are not required to do anything that would be harmful to their health (see INSTITUTIONAL REVIEW BOARDS).

V

VALIDATE: To confirm or make true. To give official sanction or approval. In clinical trials, it is the process by which the correctness of data are established.

VIRUS: An organism, smaller than bacteria, that causes infections like influenza, viral pneumonia, colds, and hepatitis (see BACTERIA and PNEUMONIA).

VISCOSITY (VISCOUS): Thickness of a fluid, tendency of the fluid to be thick, syrupy, and/or sticky.

VITAL CAPACITY (VITAL CAPACITIES): The amount of air that can be breathed out after taking the largest possible breath.

W

WASHOUT PERIOD: A time during a clinical trial when participants receive no drugs for the study so the effects of previous study drugs are removed.

WITHDRAW: The point at which a clinical trial participant, for any reason, stops participating in the trial.

**Glossary was put together with the help of these resourceful websites:*

- *http://www.cff.org/research/ClinicalResearch/Glossary/*
- *http://www.thevest.com/resources/glossary.asp#b*
- *http://www.cfliving.com/resources/glossary.jsp*