Blooming Rose FOUNDATION FOR CYSTIC FIBROSIS

FC FOUNDATION CARE
Your Full Service Cystic Fibrosis Pharmacy

CF 101:

Version Two

The Blooming Rose Foundation

the bloom•ing rose foun•da•tion

1 : educational and advocacy organization
2 : organization created to support families and patients living with cystic fibrosis
3 : established 2009

Maylie & Kat Porco

CONTACT

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FOUNDATION FOR CYSTIC FIBROSIS

ABOUT BRF

The Blooming Rose Foundation (BRF) was created to give hope to families immediately following a CF diagnosis, offering support, referral and advocacy services. BRF talks with the patient community about raising a child who is thriving with CF; focusing on the positive outlook and breakthrough treatments available now and on the horizon.

In addition, BRF helps to facilitate safe, online avenues that parents and children living with CF can access to connect with their community and share experiences in this tumultuous journey. These groups can be found through the links below.

Photo courtesy Jack Gauer, Montana Video Productions, Inc

Kathleen Quinn Porco, MS., BSW., IHC

Kat Porco is a Montanan, living in a mountain village at the base of the mountains. She attended Humboldt State University to complete her Bachelor's in Social Work, graduating cum laude. Following her BSW, she attended Boston University to achieve her Master's of Science degree in Health Communications. Her work over the past seven years has been solely focused on supporting and advocating for the cystic fibrosis community. Throughout these years, she has seen first hand the disconnect between the patient and the medical community. Understanding this complex relationship, Kat felt that she could assist in bridging the gap to reach the ultimate health goals of both parties. In order to be prepared to create lasting change in the community she attended Duke Integrative Medicine to become an Integrative Health Coach. Kat has written numerous blogs for the CFF and Make-A-Wish, sits on the editorial board of Cystic Fibrosis Research News, speaks at CF Family Days and has presented at NACFC in 2014 & 2015.

Parenting Kids with CF *(DOB 2016-2018)*
https://www.facebook.com/groups/CFDOB20162018/

Parenting Kids with CF *(DOB 2014-2015)*
https://www.facebook.com/groups/CFDOB201415/

Parenting Kids with CF *(DOB 2013-2011)*
https://www.facebook.com/groups/CFDOB20112013/

Parenting Kids with CF *(DOB 2010-2008)*
https://www.facebook.com/groups/CFDOB20082010/

Parenting Kids with CF *(DOB 2005-2007)*
https://www.facebook.com/groups/CFDOB20052007/

Parenting Kids with CF *(DOB 2002-2004)*
https://www.facebook.com/groups/CFDOB20022004/

Parenting Kids with CF *(DOB 1999-2001)*
https://www.facebook.com/groups/CFDOB19992001/

Living with CF *(DOB 1996-1997)*
https://www.facebook.com/groups/LIVINGCF19961997/

Living with CF *(DOB 1998-1999)*
https://www.facebook.com/groups/LIVINGCF19981999/

Living with CF *(DOB 2000-2001)*
https://www.facebook.com/groups/LIVINGCF20002001/

Living with CF *(DOB 2002-2003)*
https://www.facebook.com/groups/LIVINGCF20022003/

Blooming Rose Projects
https://www.facebook.com/groups/bloomingroseprojects/

CFRD
https://www.facebook.com/groups/ParentingCFRD/

Teen Non-CF Siblings
https://www.facebook.com/groups/TEENSIBLINGS/

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www.brfcf.org

TEACHING THROUGH EXAMPLE

I have spent many days trying to impart my commitment to my daughter in her fight with CF but, in the end, she feels alone. I take a moment to reprimand myself for forgetting the importance of teaching through example. Then, I focus on change.

The morning started like most mornings. I hide under the covers in painful denial of the choice that I must make: getting up and exercising. I am acutely aware of the countless benefits, both physically and psychologically, yet the covers and the comfort of my bed often win. The sound that finally brings me upright is the familiar series of coughs from the bedroom next to mine.

It shakes my body to the core, reminding me that even on Christmas morning, cystic fibrosis does not take a break. She wakes up with a smile, looks at me with those beautiful blue eyes begging for reprieve and says, “Momma -- it's Christmas, do I have to do treatment today?” I gave her the same rote response that always follows this type of question. I envelope her in a hug, and when I pull back she looks at me with the sincere naivety of a child. A small tear falls down her face as she says, “I know, but it's not fair because no one else in our family has to do something every day.” She runs upstairs, and I sit with my own tears and emotions for a moment.

I start thinking about the beautiful view that carries me along the run at my parent's house on Flathead Lake. Motivated by the view swirling in my head, I decide to put on my much-neglected running shoes to clear my head. I immediately feel the cold penetrate my lungs: tight and uncomfortable. My shoes hit the icy pavement with rhythm and steadfastness. I decide where to turn around based on the reward of viewing the overlook of the cherry orchard with the lake spanning the eye's view. As I run up and down the hills along the lake, I think of nothing other than my daughter's comment to me.

I have spent many days trying to impart my commitment to her in her fight with CF but, in the end, she feels that she is the only one sacrificing. My heart aches with grief that she feels so alone. So I make a decision, and just not a New Year's resolution that will be fickle and will eventually fade. I make a commitment to my daughter, my hero. I will be her role model. I will become her partner in her fight against CF. I will exercise every day, not because I want to, but as a testament to my daughter and the hurdles in her life. I take a moment to reprimand myself for forgetting the importance of teaching through example. Then, I focus on change. Any time my adherence waivers, I will look to her commitment and it will be my new motivation. She gets no days off, has no immediate rewards and yet day in, day out, she follows the treatment plan that has been chosen for her.

I pick up my pace as I am about to reach the top of the final hill and the view that awaits me. As I arrive, my heart sinks. The fog still hovers over the lake and orchard, and all I can see is the fence surrounding the apple trees. I want to stop and cry at this reward that I cannot claim. I immediately realize that this anticlimactic end is more common than not for my daughter. She often sees the course that lies ahead, but then something, like a bacterium, is introduced and additional treatments are thrown at her. More antibiotics and GI distress follow, and doctor's appointments take over where play dates should be.

Today marks the first day of the rest of my life. And I will use it to encourage and lead my hero through the foggy views that lie ahead.

Foundation Care Pharmacy

foun•da•tion care phar•ma•cy

1 : Independent Full Service Cystic Fibrosis Pharmacy
2 : created to serve the healthcare needs of cystic fibrosis patients
3 : established 2004

CONTACT
Foundation Care Pharmacy

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Blooming Rose FOUNDATION FOR CYSTIC FIBROSIS

FC FOUNDATION CARE Your Full Service Cystic Fibrosis Pharmacy

Mike Schultz & Dan Blakeley

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 for 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, 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 may also recommend patient and copay assistance programs to 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.

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

Verified Internet Pharmacy Practice Sites (VIPPS)
Prescription Drug Dispensing via Internet

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

Verified-Accredited Wholesale Distributors (VAWD)
Drug Distribution Accreditation

Pharmacy Compounding Accreditation Board (PCAB)
Compounding Accreditation

Better Business Bureau (BBB)

FC SPECIALS & PROMOTIONS

*Cayston®

For every fill of your Cayston prescription, choose to add hypertonic saline, Replesta, or ChoiceFul vitamins to your order at no cost.

*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 at no cost.

*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, choose to add hypertonic saline, Replesta, or ChoiceFul vitamins to your order at no cost.

*TOBI® Podhaler™

For each fill of your TOBI Podhaler prescription, Foundation Care will provide you with ChoiceFul™ Vitamins and Hypertonic Saline at no cost.

*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 a decade 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

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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

YouTube
www.youtube.com/FoundationCare

Pinterest
http://pinterest.com/foundcare/

Social media and email are not appropriate methods to send our pharmacists clinical questions. The best way to protect private health information is to call us at 877-291-1122 and ask to speak to a representative directly.

Assistance Program

as•sis•tance pro•grams

1 : financial, educational, and emotional support
2 : resources for families and individuals seeking information and support for cystic fibrosis
3 : company, patient and state assistance programs

Nick Talbot, 40

Follow Nick on Twitter!
@CF_vs_Everest

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FC FOUNDATION CARE Your Full Service Cystic Fibrosis Pharmacy

Patient Assistance Programs

Update #1
September 2016

CHIESI

PROGRAM: Chiesi CareDirect®

DESCRIPTION: Is a free service that offers prescription access support, financial assistance, and product counseling to patients.

WEBSITES:

- http://patient.bethkis.com/patient-access/
- http://www.pertzyecf.com/patient/free-support-and-savings/

PHONE: 1- 888-865-1222

EMAIL: chiesicaredirect@caremetx.com

PARI

PROGRAM: PARI PROVIDE Compressor Access

DESCRIPTION: Offers compressor access for the DeVilbiss Pulmo-Aide® model 5650D to work with the nebulizer in the Kitabis Pak.

WEBSITE: http://kitabis.com/patient-access/pari-provide-compressor-access/

PHONE: 1-844-KITABIS (548-2247)

VERTEX

PROGRAM: Vertex GPS: Guidance & Patient Support

DESCRIPTION: The Vertex GPS team will help to guide you through your insurance coverage during your KALYDECO® or ORKAMBI™ treatment experience.

WEBSITE: www.vertexgps.com

PHONE: 1-877-752-5933 (press 2)

Financial assistance offers may not be available in all areas. These offers are good for qualified customers only. These offers are not valid for prescriptions purchased under Medicaid, Medicare or similar federal or state programs or where prohibited by law.

Medications & Treatments

med•i•ca•tions & treat•ments

1 : substances or preparations used to treat cystic fibrosis and related diseases
2 : the actions or manner of treating patients medically or surgically
3 : prescription and over-the-counter medications, dietary supplements, breakthrough treatments

Somer Love, 37

Follow Somer

www.lovetobreathe.com
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Twitter: @Love_To_Breathe
FB: lovetobreathe

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CF Diagnosis & Testing

Update #1
September 2016

Carrier Testing

Carrier testing can be done for those who are planning a family and have a family history of CF. A genetics counselor or health care provider would order a blood or saliva test to find out if there is a risk of a child having cystic fibrosis.

Newborn Screening

As of 2010, all 50 states and the District of Columbia require every newborn to be screened for CF for the earliest possible diagnosis – to ensure treatment begins immediately. Newborns are screened using a blood test to check for high levels of immunoreactive trypsinogen (IRT), which shows pancreas functionality, or a genetic test, which will reveal a faulty CFTR gene. If the newborn tests positive, then a sweat test is conducted to measure the amount of salt in the sweat. The sweat test is performed twice, with high levels of salt confirming the diagnosis.

Prenatal Screening

Prenatal screening may be performed through amniocentesis and chorionic villus sampling (CVS). Amniocentesis involves removing a small amount of fluid from the sac around the baby and testing for the normalcy of both CFTR genes. With CVS, a tissue sample taken from the placenta is tested.

Postnatal Screening

It is important for older children and adults who were not screened at birth to know the signs and symptoms of CF. If there are symptoms, such as a history of recurring pancreatitis, chronic lung or sinus infections, nasal polyps, or bronchiectasis, genetic and sweat tests may be performed. Common symptoms include:

- Very salty-tasting skin
- Persistent coughing, at time with phlegm
- Wheezing or shortness of breath
- Poor growth or poor weight gain in spite of a good appetite

Post Diagnosis Testing

After a diagnosis is made, other tests may be recommended. These tests include:

- **Genetic Tests** – Determine the type of CFTR defect causing CF
- **Imaging Tests** – X-rays, CT scans and an MRI may be needed to monitor lungs or intestines
- **Lung Function Tests** – Measure the size of the lungs, the quantity and time of breathing in and out
- **Sputum (spit) Culture** – Analyze for bacteria. Certain bacteria indicate more advanced CF
- **Organ Function Tests** – Measure the health of the pancreas and liver

Information provided by:
The Mayo Clinic: http://www.mayoclinic.org/diseases-conditions/cystic-fibrosis/basics/tests-diagnosis/con-20013731
The National Heart, Lung, and Blood Institute: http://www.nhlbi.nih.gov/health/health-topics/topics/cf/diagnosis
The Cystic Fibrosis Foundation: http://www.cff.org/AboutCF/Testing/

Medications & Treatments

Update #1
September 2016

ANTIBIOTICS

BETHKIS®

(Tobramycin Inhalation Solution) is indicated for the management of cystic fibrosis patients with Pseudomonas aeruginosa. It is a concentrated solution delivering 300 mg of nebulized tobramycin in only 4 mL. The solution offers osmolarity similar to that of airway surface liquid in patients with cystic fibrosis. For more information, visit: www.bethkis.com/

KITABIS® PAK

The Kitabis Pak is the first FDA approved convenience kit that combines Tobramycin Inhalation Solution and the PARI LC PLUS® Reusable Nebulizer under one prescription. This kit is for cystic fibrosis patients 6 years of age and older who have Pseudomonas aeruginosa.

Product Benefits

With the drug and the device packaged together, it can be a simpler option for patients. There is no hassle with device co-pays, co-insurance, deductibles, or other treatment delays. Patients take the treatment two times each day for 28 days on and 28 days off. The entire treatment should take approximately 15 minutes to complete.

*Many CF patients already own a Pulmo-Aide® compressor. Those who don't can contact their physician for a prescription, or get one through the PARI PROVIDE Access Program.

For more information, visit: http://kitabis.com/

GENE THERAPY

KALYDECO® (ivacaftor)

KALYDECO is a prescription medicine used for the treatment of cystic fibrosis (CF) in patients age 2 years and older who have one of the following mutations in their CF gene: G551D, G1244E, G1349D, G178R, G551S, S1251N, S1255P, S549N, or S549R. KALYDECO is used for the treatment of CF in patients age 2 years and older who have an R117H mutation in their CF gene. KALYDECO is not for use in people with CF due to other mutations in the CF gene. KALYDECO is not effective in patients with CF with two copies of the F508del mutation (F508del/F508del) in the CF gene. It is not known if KALYDECO is safe and effective in children under 2 years of age.

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

ORKAMBI™ (lumacaftor/ivacaftor)

ORKAMBI (lumacaftor + ivacaftor) is a prescription medicine used for the treatment of cystic fibrosis (CF) in patients 6 years and older who have two copies of the F508del mutation of their CFTR gene. ORKAMBI should not be used in patients other than those who have two copies of the F508del mutation in their CFTR gene. It is not known if ORKAMBI is safe and effective in children under 6 years of age.

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

Medications & Treatments

Update #1
September 2016

Mucus Clearance

PulmoSal™ (7%, pH+)

PulmoSal 7% (pH+) is a 2nd Generation Bio-Balanced™ Hypertonic Saline. It is indicated for use in conjunction with a nebulizer for the induction of sputum where sputum production is indicated.

Vitamins

DEKAs®

Callion Pharma recently launched the DEKAs® line of nutritional supplements, the next generation of multivitamin and mineral dietary supplements for enhanced absorption of fat-soluble vitamins and other micronutrients. DEKAs products utilize a delivery technology that helps patients overcome micronutrient malabsorption and lead healthier lives.

Pipeline

This information is current as of September 2016.

Ataluren (also know as Translarna™) *(Restore CFTR Function)*

Ataluren (Translarna™) is a novel, small molecule compound designed to enable production of a full-length and functional CFTR protein in individuals with CF who have nonsense mutations. The compound helps the body override a premature signal to stop production of the CFTR protein. A Phase 3 trial completed in 2011 showed that study participants who received ataluren had a lower decline in lung function and a lower rate of pulmonary exacerbations, compared with those who took a placebo. A new Phase 3 trial is ongoing for people with CF who have nonsense mutations and are not taking aminoglycosides. This program is sponsored by PTC Therapeutics and partially funded by Cystic Fibrosis Foundation Therapeutics (CFFT). The program is being conducted within CFFT's Therapeutics Development Network.

CTX-4430 *(Anti-Inflammatory)*

CTX-4430 is an oral anti-inflammatory drug that reduces production of LTB4, a molecule that leads to inflamation and is known to be elevated in people with CF. Reduction of inflammation may help stabilize lung function. A phase 2 trial is currently underway. This program is sponsored by Celtaxsys and partially funded by Cystic Fibrosis Foundation Therapeutics (CFFT). It is being conducted within CFFT's Therapeutics Development Network.

FDL169 *(Restore CFTR Function)*

FDL169 is a new CFTR corrector. Correctors are drugs designed to fix and restore the function of the defective CFTR protein. The corrected CFTR then moves to the cell surface, where it functions as a chloride channel and helps maintain the right balance of fluid in the airways. A phase 2 study to test the safety of this compound on those with two copies of the F508del CFTR mutation will begin soon. This program is sponsored by Flatley Discovery Lab. It is being conducted within the Cystic Fibrosis Foundation's Therapeutics Development Network.

Gallium *(Anti-Infective)*

Gallium is a molecule, nearly identical to iron, that disrupts iron-dependent biological processes and has been shown to kill antibiotic-resistant strains of Pseudomonas aeruginosa in laboratory research. Gallium has already been approved by the FDA for intravenous use in people and is now being studied for its safety and

effectiveness in controlling P. aeruginosa in people with CF. A phase 2 trial is underway. This program is sponsored by the Cystic Fibrosis Foundation Therapeutics and is being conducted within CFFT's Therapeutics Development Network.

GS-5745 *(Anti-Inflammatory)*

GS-5745 is an antibody that may help reduce inflammation in the lungs, leading to improved lung function in people with CF. A phase 2 study to test the effectiveness of GS-5745 in adults with CF will begin soon. This program is sponsored by Gilead. It is being conducted within the Cystic Fibrosis Foundation's Therapeutics Development Network.

Inhaled Levofloxacin *(Anti-Infective)*

Inhaled levofloxacin (Quinsair™) is a formulation of the antibiotic levofloxacin for the management of chronic lung infections caused by Pseudomonas aeruginosa and other bacteria. Inhaled levofloxacin has been approved in the European Union and Canada for adults with CF. A Phase 3 trial in the United States has been completed. The program is sponsored by Raptor Pharmaceuticals, Inc. and supported by Cystic Fibrosis Foundation Therapeutics (CFFT). It was conducted within CFFT's Therapeutics Development Network.

Inhaled Liposomal Amikacin (also known as Arikace™) *(Anti-Infective)*

Inhaled liposomal amikacin (Arikace™) is an antibiotic that is being used to treat chronic lung infections caused by nontuberculous mycobacteria (NTM). A Phase 3 trial for the treatment of nontuberculous mycobacteria (NTM) was completed in 2015. The program is sponsored by Insmed Incorporated and partially funded by Cystic Fibrosis Foundation Therapeutics. It is is being conducted within CFFT's Therapeutics Development Network.

Inhaled Mannitol (also known as Bronchitol®) *(Mucociliary Clearance)*

Bronchitol is an inhaled dry powder form of mannitol (a naturally occurring osmotic agent), which works by drawing water into the airways, moistening and thinning the sticky mucus found in the lungs of people with CF, thereby making it easier to cough it out. A phase three trial of Bronchitol is currently underway. The program is sponsored by Pharmaxis and is being conducted within CFFT's Therapeutics Development Network.

Inhaled Nitric Oxide *(Anti-Infective)*

Nitric oxide is a gas with antimicrobial properties that may reduce lung infections when inhaled, leading to improved lung function in people with CF. A phase 2 study to test the safety and effectiveness of inhaled nitric oxide in adults with CF will begin soon. This program is sponsored by Novoteris and partially funded by Cystic Fibrosis Foundation Therapeutics (CFFT). It is being conducted within the Cystic Fibrosis Foundation's Therapeutics Development Network.

JBT-101 *(Anti-Inflammatory)*

JBT-101 (Resunab™) is an oral drug that is aimed at promoting the resolution of inflammation. It is thought to increase production of anti-inflammatory molecules while reducing production of molecules that increase inflammation. Reduction of inflammation helps prevent permanent tissue damage in the lungs. A phase 2 trial is underway. This program is sponsored by Corbus and partially funded by the Cystic Fibrosis Foundation Therapeutics (CFFT). It is being conducted within CFFT's Therapeutics Development Network.

Liprotamase *(Nutritional-GI)*

Liprotamase (Sollpura™) is a pancreatic enzyme replacement that is not prepared from animal sources. An ongoing Phase 3 trial, will look at the safety and effectiveness for people with CF ages 7 years and older. A previous Phase 3 trial showed that there were no safety concerns, and the coefficient of fat absorption

improved. The program is sponsored by Anthera Pharmaceuticals and partially funded by Cystic Fibrosis Foundation Therapeutics. It is being conducted within CFFT's Therapeutics Development Network.

N91115 *(Restore CFTR Function)*

N91115 is a new oral compound that modulates the function of the defective CFTR protein and decreases inflammation in the lung. N91115 is the first of a new class of compounds that increase levels of an important signaling molecule in the body, called S-nitrosoglutathione or GSNO. Levels of GSNO have been shown to be decreased in people with CF. These novel compounds have been shown to increase the amount of CFTR that reaches the cell membrane and to stabilize CFTR so that its function can be improved. Two phase 2 studies of N91115 in people with CF are underway. The studies will look at the safety and effectiveness of N91115 in people who have one or two copies of the F508del mutation. The program is sponsored by Nivalis Therapeutics Inc. and is being conducted within CFFT's Therapeutics Development Network.

OligoG *(Mucociliary Clearance)*

OligoG is a dry powder drug that has been shown to decrease the thickness of mucus in the lungs and may help individuals with cystic fibrosis clear mucus easier. OligoG may also help improve the effectiveness of some antibiotics. It is administered using a dry powder inhaler and also developed as a liquid for use with a nebulizer. Two phase 2b trials are ongoing in the United Kingdom, Germany, Sweden, Denmark and Norway. This program is sponsored by AlgiPharma and partially funded by the Cystic Fibrosis Foundation Therapeutics (CFFT). It is being conducted within CFFT's Therapeutics Development Network.

QBW251 *(Restore CFTR Function)*

QBW251 is a type of CFTR Modulator called a “potentiator”, similar to the drug ivacaftor, this drug would help to facilitate the opening of the chloride channel on the cell surface. This compound is administered through an oral pill. Phase 2a trials were completed in individuals with residual function mutations. This program is sponsored by Novartis and is being conducted within CFFT's Therapeutics Development Network.

QR-010 *(Restore CFTR Function)*

QR-010 is an oligonucleotide designed to repair CFTR encoded mRNA, which could result in a wild-type or normal CFTR protein in people that have one or two copies of the F508del mutation. It is delivered via inhalation. A Phase 1b trial to assess the safety and tolerability of QR-010 is underway. Another Phase 1 trial that is underway is a proof of concept study to evaluate the effect of QR-010 on nasal CFTR function. This program is sponsored by ProQR Therapeutics and partially funded by Cystic Fibrosis Foundation Therapeutics (CFFT). It is being conducted within CFFT's Therapeutics Development Network.

Riociguat *(Restore CFTR Function)*

Riociguat is a novel therapy that stimulates sGC, an enzyme in the cardiopulmonary system and the receptor for nitric oxide (NO). Preclinical data has shown evidence that riociguat can result in improved CFTR channel expression. A Phase 2 trial is underway in adults who have two copies of the F508del mutation. This program is sponsored by Bayer and is being conducted within CFFT's Therapeutics Development Network.

Vancomycin Inhalation Powder (also known as AeroVanc™) *(Anti-Infective)*

Vancomycin inhalation powder (AeroVanc™) is an inhaled dry powder version of the antibiotic vancomycin for the treatment of methicillin-resistant Staphylococcus aureus (MRSA) airway infection in people with CF. Results from a U.S. multicenter Phase 2 trial showed that study participants who received AeroVanc™ experienced a significant reduction in MRSA density in their sputum compared with those given a placebo. This program is sponsored by Savara Pharmaceuticals and partially funded by Cystic Fibrosis Foundation Therapeutics. It is being conducted within CFFT's Therapeutics Development Network.

VX-371 (formerly P-1037) *(Mucociliary Clearance)*

VX-371 is a drug that blocks the sodium channel in airway cells. By blocking this channel, the drug may prolong the duration that fluid in the airways can be maintained after hypertonic saline use. The more fluid in the lungs, the thinner the mucus and the easier it is to clear. A phase 2 trial is underway. This program is sponsored by Vertex Pharmaceuticals Inc. and Parion Sciences and partially funded by Cystic Fibrosis Foundation Therapeutics (CFFT). It is being conducted within CFFT's Therapeutics Development Network.

VX-661 + Ivacaftor *(Restore CFTR Function)*

This trial is testing VX-661 in combination with ivacaftor. VX-661 is a compound, called a “corrector,” designed to move defective CFTR protein to the proper place in the airway cell membrane and improve its function as a chloride channel. A Phase 2 trial for people with CF who have two copies of the F508del mutation was completed January 2015. Several Phase 3 trials are underway in people who have one or two copies of the F508del mutation. This program is sponsored by Vertex Pharmaceuticals Inc. and partially funded by Cystic Fibrosis Foundation Therapeutics. The program is being conducted within CFFT's Therapeutics Development Network.

Nebulizers

neb•u•liz•er

1 : deliver medications quickly - directly to the respiratory tract
2 : deliver liquid or aerosol medications to your lungs via a mask or mouthpiece
3 : available in a portable variety or powered by compressed air and plugged into an electrical outlet

Jessica Bean, 28

Follow Jessica

www.jessicabean.com.au
FB: healthempowermentcoach
IG: jessicabeancoach

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FC FOUNDATION CARE Your Full Service Cystic Fibrosis Pharmacy

Nebulizers

Update #1
September 2016

COMPRESSORS

The Compressor creates an airflow which travels down to the nebulizer through tubing. The Nebulizer is the medicine cup that turns medication into a mist or aerosol.

PARI Trek® S Portable Aerosol System

The PARI Trek® S Portable Aerosol System is designed for fast, efficient aerosol treatments with portable technology. It's perfect for those with active lifestyles by allowing patients to take treatments anywhere.

All configurations include a PARI Reusable Nebulizer and backup reusable nebulizer, Trek® S Compressor, Timestrip®, Wing-Tip™ tubing, AC Adapter, 12V DC Adapter, Instructional DVD, and Deluxe Carrying Case.

PARI Vios® Aerosol Delivery System

The new "Go Green!" PARI Vios® is available in Standard and Pediatric configurations. Here's what changed:

- Color is Emerald Green
- A new carrying case features 100 percent recycled material
- Access to instructional videos online, eliminating DVD waste
- Packaging made from recycled material

All configurations include a PARI Reusable Nebulizer and backup reusable nebulizer, Vios® Compressor, Timestrip®, Wing Tip® tubing.

PARI Vios® PRO Aerosol Delivery System

The Vios® PRO Aerosol Delivery System was designed for heavy use patients. Its powerful and durable 1.6 bar compressor delivers the highest pressure output for efficient, consistent, and dependable daily use.

All configurations include a PARI Reusable Nebulizer and backup nebulizer, Vios® PRO compressor, Timestrip®, Vios® PRO tubing.

Contact

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

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

**All information on this page was found on PARI's official website at http://www.pari.com/products/compressors.html*

Airway Clearance

air•way clear•ance

1 : loosen thick, sticky lung mucus so it can be cleared by coughing or huffing
2 : clearing the airways reduces lung infections and improves lung function
3 : ACT - airway clearance technique
4 : ACTs should be administered or supervised by an adult in infants and toddlers
5 : older children and adults should be capable of administering their own ACTs (depending on technique chosen)

Chris Kvam, 36

Read about Chris
www.cflf.org/blog/top-15

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Airway Clearance

Update #1
September 2016

SmartVest ® SQL® System for in-home HFCWO

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 SQL was designed with input from current SmartVest users. They said they wanted a device that was easier to take along and easier to use while doing the things they loved. So Electromed reengineered their easy-to-use and effective system, making the air-pulse generator: 25% smaller, 5dB quieter, and 25% lighter.

Product Benefits

The SmartVest garment is available in a variety of colors and eight chest sizes ranging from 16 inches (41 cm) to 52 inches (132 cm). An extender is also available for adult-size garments, capable of adding up to 14 inches (36 cm) to the chest circumference.

Each SmartVest SQL System for in-home care includes:

- •Washable SmartVest garment
- •Programmable, multi-position, ultra-quiet SmartVest SQL generator
- •Connection hose
- •Lifetime warranty
- •Instruction manual and training DVD
- •Patient, caregiver and clinician support services, including:
  - ◦Insurance reimbursement assistance
  - ◦No-risk trial period
  - ◦In-home training by a licensed professional
  - ◦Toll-free patient and caregiver helpline (888.966.2525)
  - ◦A dedicated Patient Services team, staffed by licensed respiratory therapists

Reimbursement

The SmartVest Airway Clearance System is available only with a physician's prescription. The cost of HFCWO therapy is generally reimbursed by private insurance, Medicare, a state medical assistance program, a combination of the three, or the U.S. Department of Veterans Affairs.

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/.*

Airway Clearance

Vibralung® Acoustical Percussor

The Vibralung Acoustical Percussor applies vibratory sound waves, during inspiration and exhalation, over a wide range of frequencies (5 to 1,200 Hz) to vibrate the column of gas in the tracheobronchial tract. As a result, mucus is loosened and separated throughout the airways, by the principle of sympathetic resonance, to promote safe, effective and gentle airway clearance therapy.

Product Facts

The Vibralung® Acoustical Percussor is intended for use in the hospital or at home for patients with respiratory diseases and related conditions. Acoustical energy (sound waves) is coupled directly to the patient's airway through a unique Hand-held Transducer (HHT) that contains a small high-fidelity loudspeaker. The HHT connects to the Treatment Control Unit (TCU) via a cable. The TCU can be held by the patient, positioned on a nearby table or even pole-mounted. The lightweight HHT is ergonomically designed for easy handling by patients of all ages.

Product Benefits

The Vibralung® Acoustical Percussor is a gentler form of airway clearance therapy (ACT) than oscillatory PEP devices, or those that make contact with the external chest wall. It may be useful in conditions where other means, such as vests and hand-held percussors, cannot be used, such as with patients who have chest wall injuries, burns, fresh surgical wounds, or injured/broken ribs.

Each Vibralung® Acoustical Percussor offers these advantages:

- Easy to operate; battery-powered, lightweight and portable
- Requires minimal patient effort with normal breathing
- No discomfort; no contact with external chest wall
- Quick and efficient treatment times
- Sole therapy or adjunct to other methods/devices
- Optional simultaneous aerosol delivery
- Incorporates PEP (Positive Expiratory Pressure)
- Works during both phases of the breathing cycle

Reimbursement

Insurance companies are currently evaluating their coverage of the Vibralung Acoustical Percussor on an individual basis. More and more insurance companies are reimbursing for the device. In some cases insurance coverage is denied intially but then later covered after an appeal documenting medical necessity. There is an income-based Patient Financial Assistance program to patients who are cash or private pay.

Contact:

Westmed, Inc.
5580 S. Nogales Highway
Tucson, AZ 85706-3333
Phone: 800-889-5231

Website: http://www.vibralung.com/

**All information on this page was found on Westmeds official website at http://www.vibralung.com/*

Airway Clearance

Update #1
September 2016

Med Systems Electro Flo® 5000

The Electro Flo® 5000 is a high speed hand held hammer that when pressed against the chest replaces manual percussion. The Electro Flo® 5000 with Force-Multiplying Technology is convenient to use and great for travel. With its compact travel case the Electro Flo® 5000 weighs only 5.50 pounds.

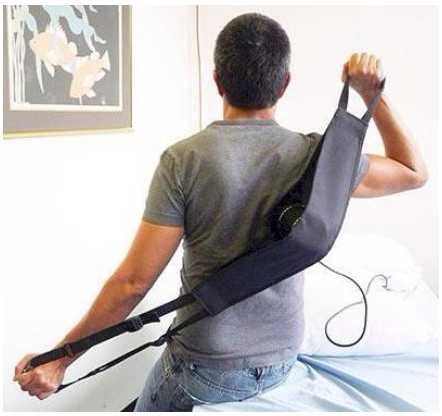
Product Facts

The Electro Flo® 5000 can be placed on the exact congested location to loosen and dislodge trapped bronchial secretions. This postural drainage device is more effective than a flutter device, massager, IPV, or vest. It is less tiring to administer and more effective than manual percussion.

Product Benefits

MED SYSTEMS is providing ELECTRO FLO® 5000 demo units to cystic fibrosis and other out patient clinics upon request. Check with your local clinic for a demonstration and recommendation. If your local clinic doesn't have a unit ask them to call Med Systems Sales Department at 800-345-9061.

- Is true automated hand percussion. It's not a massage tool, vibrator or oscillator.
- Delivers smooth, deep pulses and is much faster than flutter devices.
- Precisely controls power and frequency of percussion separately. It's light-weight and can be self-administered to individual lobes.
- Has a 3-prong hospital grade plug on a 10 foot cord that plugs into a standard electrical receptacle 120 VAC, 50/60 Hz.
- May be run from your car, truck, RV or boat with an approved power inverter.
- Has a three year parts and labor warranty.
- May be tried free for 30 days and returned if not completely satisfied.
- The case measures 11″ x 10″ x 5″



Reimbursement

The Electro 5000 is available with a physician's prescription. Some private insurance policies do cover a percentage of the cost. The average reimbursement is about 80%. Med Systems will send a demo to try for 30 days. They also offer a 30 day money back guarantee.

Contact:

Med Systems, Inc.
2631 Ariane Dr.
San Diego, CA 92117
Phone: 800-345-9061

Website: www.medsystems.com

**All information on this page was found on Med Systems official website at http://www.medsystems.com/*

Non-Profit Organizations

non•prof•it or•ga•ni•za•tion

1 : does not declare a profit
2 : utilizes all revenue after normal operating expenses in service to the public interest
3 : organized under state law
4 : operated for a 501(c) 3 purpose
5 : engages in activities that are non-political in nature
6 : derives at least one-third of its support from the general public

Emily Schaller, 34

Follow Emily
www.letsrockcf.org
IG: rockcfem
Twitter: @rockcfem

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Breathe Easy With Us

Our goal, and the reason we ask you to Breathe Easy With Us is to touch lives in a very direct and engaging way. The Cystic Fibrosis Foundation and many of the amazing organizations out there are impacting the CF community through funding and research development. It's in our heart, to connect directly with CF patients in need, and drop care packages of love from the sky directly into their lap. It is a secondary, yet just as important goal, that we put the education in the minds and tools in the hands of the CF community on a global scale. We do this so that they can take their health into their own hands and improve their quality of life far beyond any statistics or text book recordings.
www.breatheeasywithus.com

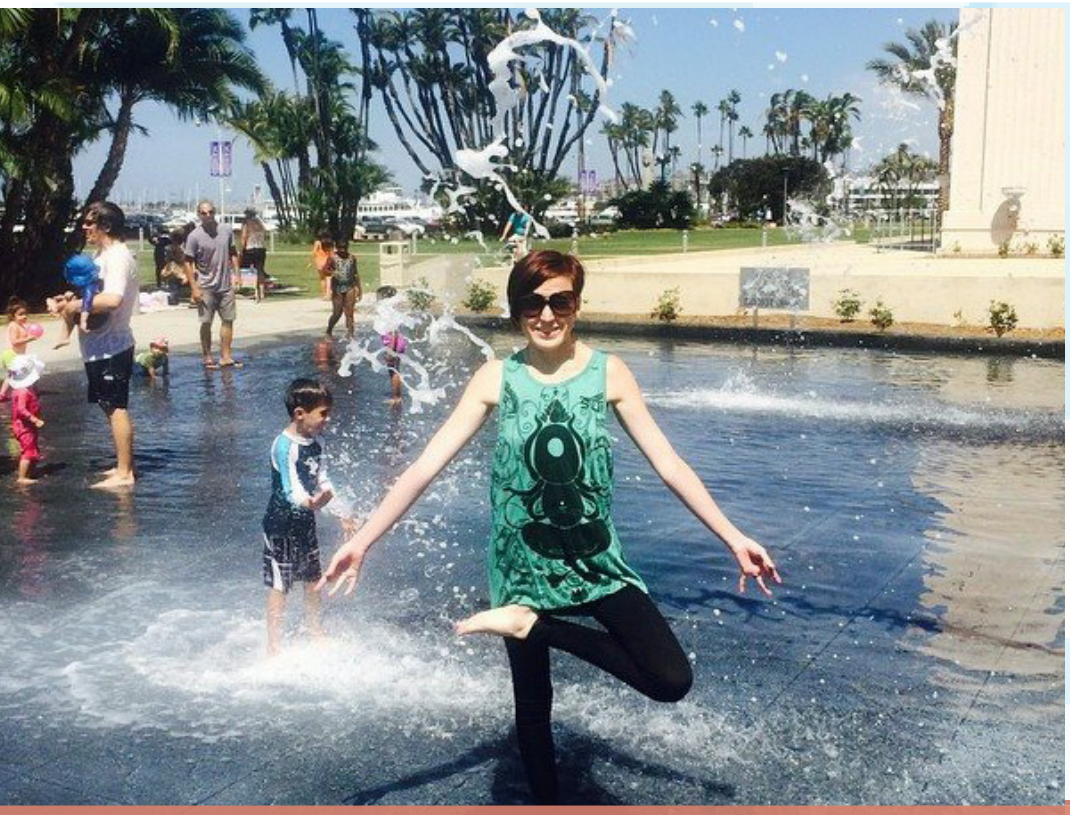
BEWU Headquarters
1832 S Claremont Ave
Independence, MO 64052
BreatheEasyWithUs@gmail.com

Resource Materials

re•source ma•te•ri•al

1 : a source of supply, support, or aid, especially one that can be readily drawn upon when needed

2 : a group of ideas, facts, data, etc., that may provide the basis for or be incorporated into some integrated work



Aimee Lecointre, 31

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FB: thenourishedbreath

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Resource Materials: BOOKS

Update #1
September 2016

Huxi Goes on Vacation! — Foundation Care Pharmacy

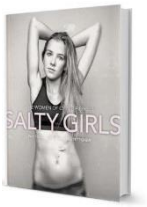
The second Huxi coloring book illustrating the extra steps and providing a checklist for those with CF while planning for a vacation.

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

Just Breathe: *Adults Living with Cystic Fibrosis* — Written by people with CF for people with CF; Photography by Ian Ross Pettigrew

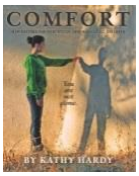
The culmination of over six months, 25 cities, and almost 6000 miles, *Just Breathe: Adults Living with Cystic Fibrosis* is a book of 92 portraits of adults living with, and surviving, cystic fibrosis. Each portrait has a personal write up, in their own words, of what it's like to live with this fatal, genetic disease.

Salty Girls: *The Women of Cystic Fibrosis* — Photography by Ian Ross Pettigrew



In this book, the Salty Girls challenge the norm and strive to put an end to body shaming. No more feeling embarrassed or ashamed of their bodies, the Salty Girls have inspired other women with CF. They embrace their body's scars and all, to inspire women everywhere to do the same. These women are the epitome of remarkable strength, enormous resilience, and unique beauty both inside and out. Not only is this book about raising awareness for cystic fibrosis, but it can reach all females who have felt this way.

Comfort: *Inspirations For Parents of Chronically Ill Children* — By Kathy Hardy



This sensitive, honest, and heartfelt devotional doesn't pull any punches. It encounters all aspects of raising a chronically ill child and helps others understand the day-to-day struggles and joys. It is eight weeks of reality: the good, the bad, and the ugly. At the end of each week of devotions, you'll find a short chapter of Kathy's family's continuing story of raising their eight children, three of whom have Cystic Fibrosis (CF). This book will touch you. It will make you laugh, cry, and feel less alone. You will feel understood and know that your journey is shared by others who experience similar emotions. You can give this book to family members and friends whom you feel lack understanding of your family's dynamics. You will feel comforted to know that God and others walk this difficult path along with you.

My Foreign Cities: *A Memoir* — By Elizabeth Scarboro

A fresh, beautiful story of young love and its greatest challenge. When she was just seventeen, independent and ambitious Elizabeth Scarboro fell in love with irreverent and irresistible Stephen. She knew he had cystic fibrosis, that he was expected to live only until the age of thirty or so, and that soon she'd have a choice to make. She could set out to travel, date, and lead the adventurous life she'd imagined, or she could be with Stephen,

who came with an urgency of his own. In choosing him, Scarboro embraced another kind of adventure—simultaneously joyous and heartrending—staying with Stephen and building a life in the ten years they'd have together. The illness would be present in the background of their lives and then ever-more-insistently in the foreground. Scarboro tells her story of fierce love and its limitations with humor, grace, and remarkable bravery. My Foreign Cities is a portrait of a young couple approaching mortality with reckless abandon, gleefully outrunning it for as long as they can.

Waiting to Die, Running to Live — By Michael Patrick Burke

This book is the fascinating account of the struggles and triumphs one faces with a chronic diagnosis. The wisdom and insight Mike Burke has gained over the years can aptly be applied to life-crisis situations on many personal levels. Everyone has his or her own battle and race, and Mike's story can inspire every reader to make it to the "finish line" with grace and strength.

Resource Materials: VIDEOS

Update #1
September 2016

TELEVISION SERIES

The Red Band Society (2014-2015)

The Red Band Society tells the story of a group of teens battling various conditions that have kept them in the hospital for an indefinite amount of time. Dash battles cystic fibrosis while Leo and Jordi fight cancer, Emma undergoes treatment for anorexia, Kara waits for a heart transplant, and Charlie, who narrates the story, lays helpless in a coma. The unconventional group of friends with only illness in common supports each other and form "The Red Band Society" when Leo shares his red bands, each representing a different surgery.

NOTABLE TV EPISODES

American Ninja Warrior: *2015 Pittsburgh Qualifiers* (NBC)

Season 7: Episode 5

Despite battling cystic fibrosis, Ryan Ripley is determined to conquer the American Ninja Warrior course at the Pittsburgh Qualifiers.

The Balancing Act, "*Behind the mystery: Rare and Genetic Diseases*"

Lifetime Network

Aired on May 15, 2015. The Balancing Act host Julie Moran sat down with Foundation Care co-founders Dan Blakeley and Mike Schultz to discuss the company's dedication to meeting the demands of cystic fibrosis patients, bringing a whole level of care to the debilitating disease. It can be seen on The Balancing Act's YouTube page at: https://youtu.be/qbbRafynvGE

Derailed (NBC)

Season 1: Episode 1

Dr. Charles finds a fighting chance for a young patient with cystic fibrosis when a victim of the train accident becomes a lifesaving lung donor.

MUSIC VIDEOS

OneRepublic, "I Lived"

OneRepublic's music video features cystic fibrosis patient Bryan Warnecke and shows his courage and drive while battling the disease. The video chronicles the daily routine and struggles cystic fibrosis patients face. It shows Bryan's courage and drive while battling the disease. In 2014, Bryan and his cycling teammates biked more than 1200 miles and raised more than $300,000 toward CF research. The video can be seen at: https://youtu.be/z0rxydSolwU

Resource Materials: VIDEOS

Update #1
September 2016

DOCUMENTARIES AND FICTIONAL FILMS

Up for Air (2016)

'Up for Air' explores the human spirit's fight for survival through the eyes of Jerry Cahill – a 53-year-old pole-vaulter who continues to fight respiratory degeneration, depression, and a potentially fatal double-lung transplant. Shot over a period of five years, Up for Air captures the fragility of life with a chronic, fatal illness as it disrupts physical, mental, interpersonal and professional well-being, and how the intersection of dedicated athleticism, self-discipline, and community outreach can achieve unprecedented outcomes.

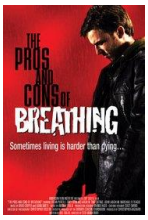
CF: Two Little Letters (2011)

The self-reflexive documentary short follows Annie Sakellar, a 23-year-old filmmaker who must cope daily with her chronic respiratory disease, Cystic Fibrosis.

Jack and Jill vs. the World (2006)

Jack is a NYC advertising executive with a life as glossy as the ads he spins. Jill is new to the city, with nothing to stand on but her fiery personality and romantic ideals. Opposites attract, and together they author their own manifesto of "rules to live by." But Jill betrays Jack by violating rule one – be honest.

The Pros and Cons of Breathing (2006)

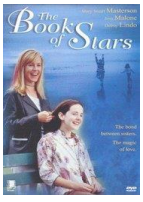


A young man with a terminal condition embraces a criminal lifestyle, taking to the streets like a new age Doc Holliday, determined to go out in a blaze of glory.

Already Gone (2012)

Jude Mulvey is a young criminal who suffers from Cystic Fibrosis – a terminal condition he's been afflicted with since birth. His criminal lifestyle is an expression of rage and an attempt to take control of his mortality. Wanting to die anywhere other than a hospital bed has made him a truly fearless (and effective) criminal. Jude leads his small crew into drug dens and mob hangouts, successfully robbing other criminals as a staple to his survival. It's a pretty effective use of Jude's talents, until he crosses the wrong mobster.

The Book of Stars (1999)



After their parents' untimely death in a car accident, Penny struggles to take care of her younger sister Mary, who suffers from cystic fibrosis. A precocious former poet, Penny has turned to prostitution as a means of support, but Mary is determined to reignite a spark of hope in Penny's life by expressing her deepest feelings in her Book of Stars. With the aid of the Professor, who is a friend and neighbor, Mary secretly corresponds on her sister's behalf with a prisoner, who is inspired by the book of poetry Penny wrote as a young girl.

The Nine Lives of Alice Martineau (2003)

This hour-long documentary, produced by BBC, shares the life and struggles of popular British pop singer, Alice Martineau. Before passing away in 2003 at 30 years old, she was a successful singer and model, and defeated death many times. Due to her cystic fibrosis, she was told on many occasions she would die much younger.

CF Care Team

CF Center Team

Primary CF Doctor and/or Director of Program

A physician with advanced training in CF care.

Primary CF Nurse / CF Coordinator

A health care professional who helps with outpatient CF care.

CF Dietitian

A health care professional trained to help with diet and growth.

CF Social Worker

A health care professional trained to provide emotional support, help access insurance or community resources, and make connections for education or counseling.

Other Team Members

Respiratory Therapist (RT)

A health care professional trained to help a person use inhaled medications correctly, set up oxygen therapy or other breathing support machines, and do airway clearance.

Physical Therapist (PT)

A health care professional trained to help a person make an exercise program that matches his or her age, health, and interests. A PT helps people recover strength and endurance. In some centers, the PT will also help with airway clearance.

Nurse Practitioner

A nurse who has more education and training than other nurses. He or she usually specializes in the care of children, teens, and/or adults who have a chronic illness, such as CF. The nurse practitioner works closely with the CF doctor to plan and carry out a health care plan for each person with CF and his or her family.

Psychologist

A health care professional who can assess a person's emotional health and how a family system is managing. The psychologist can help families find ways to problem solve, resolve difficulties, and make positive behavior changes.

Child Life Specialist (CLS)

A health care professional trained to help children and their families cope with disease and the tests and treatments required. The CLS helps children handle stress and anxiety and helps them understand what is happening in a simple way to match their abilities.

Pharmacist

A health care professional with advanced training on medications. A pharmacist specializes in appropriate use of medications, dosing and drug selection. They have advanced knowledge of medication interactions and possible side effects.

Scholarships

schol•ar•ship

1 : a sum of money or other aid granted to a student because of merit, need, etc., to pursue his or her studies
2 : specifically offered to cystic fibrosis patients
3 : offered nationally, by state, or by college/university

Jerry Cahill, 60

Follow Jerry

www.jerrycahill.com
www.youcannotfail.com
www.esiason.org
Twitter: @jcahillYCF, @YouCannotFail, @cysticfibrosis
FB: BoomerEsiasonFoundation
YouTube: Boomer Esiason Foundation

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Social Media

so•cial me•dia

1 : Websites and other online means of communication that are used to share information and to develop social and professional contacts

2 : bringing people with similar interests together, no matter where in the world they live

Rose Martini, 40

Follow Rose

www.rosierecords.com

IG: rosemartinimusic

Twitter: @RosieRecordsSF

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FC FOUNDATION CARE Your Full Service Cystic Fibrosis Pharmacy

Online Communities

Update #1
September 2016

An **online community** is a group of people who communicate with one another over the Internet, usually with a common interest.

All in for CF

www.vrtxallincf.com/voicesofcf/

The cystic fibrosis community is all in – dedicated to supporting, educating, and inspiring others every day. Vertex is celebrating the people living with CF, their family members, caregivers, friends, healthcare providers, advocates, and other community members who go the extra mile to make a difference. Each month, Vertex will profile members of the CF community who are "All in for CF."

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.

**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 feel it would be a good addition to this list, please send the information to:*

help@foundcare.com

Mental Health

men•tal health

1 : maintaining and/or treating positive health beyond physical symptoms
2 : should be treated as part of your overall health and emotional wellness

Josh Mogren, 37

Follow Josh

www.mogankoforcf.org
FB: Moganko
YouTube: welcometojoshland

Depression & CF

Update #1
September 2016

"Research has shown that people with long term health conditions are more likely to experience mental health issues such as anxiety and depression than the general public. Family members, partners and caregivers of people with serious, long term health problems are also more likely to experience anxiety and depression. We see the same trends happen in people with CF and families impacted by CF – especially during times of change (such as newly diagnosed families, starting school, leaving home etc) or during changes in health (such as first admissions, CF-related diabetes diagnosis, CF-related pain, wait listing for transplant).

Feelings of worry and sadness are a normal part of life. There are good reasons why you might feel worried or sad, especially if you or your child has CF. Sometimes it is hard to know if the worry and sadness you are experiencing is normal or might be symptoms of anxiety and depression. The best way to find out is to have a discussion with a health professional about how you are feeling and coping. If you are finding that your feelings are impacting significantly on your daily life, are limiting your activities, or are stopping you from enjoying the things you do, then there is a chance you are experiencing symptoms of anxiety or depression.

If you, or someone you love, are experiencing anxiety or depression, it's important to seek help. Unmanaged mental health symptoms negatively impact your physical health, and can get in the way of effective CF management. There are many ways that you can get the help you need, and many different places you can access counselling and psychology services."

Excerpt taken from *"Anxiety, Depression and Cystic Fibrosis – Where Can I get Help?"* by Lou Walsh
https://louwalsh.wordpress.com/2015/03/11/anxiety-depression-and-cystic-fibrosis-where-can-i-get-help/

TIDES: The International Depression / Anxiety Epidemiological Study

Website: http://tides-cf.org/

Many studies have shown that patients with chronic illnesses are at increased risk for depression and anxiety. To date, there has been no systematic evaluation of depression and anxiety in patients with CF and parent caregivers. The purpose of this study is to conduct the first international epidemiological study of depressive and anxious symptoms in the population.

Progress Notes (United States)

- Study has been funded by the Cystic Fibrosis Foundation.
- Over 60 Centers have expressed interest.
- Approximately 25 centers are collecting data.
- A big push is being made to recruit an additional 30 centers in the US.

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ARTICLES, BLOGS & JOURNALS

Anxiety and Depression in Cystic Fibrosis
By Ivette Cruz, M.S., Kristen K. Marciel, Ph.D., Alexandra L. Quittner, Ph.D., and Michael S. Schechter, M.D., M.P.H.
Posted by Department of Psychology, University of Miami
http://www.researchgate.net/publication/26818184_Anxiety_and_Depression_in_Cystic_Fibrosis

Can Depression Make Lung Function Worse in CF Patients? (December 2014)
By Alisa Woods, PhD
Posted by Cystic Fibrosis News Today
http://cysticfibrosisnewstoday.com/2014/12/22/depression-makes-lung-function-worse-cf/

Cystic Fibrosis and Depression
Posted by Nationwide Children's (Columbus, OH)
http://www.nationwidechildrens.org/cystic-fibrosis-and-depression

Depression and Anxiety among Parents of Children with Cystic Fibrosis Related to the Children's Health Related Quality of Life (May 2015)
By Agneta Bergsten Brucefors, Jacek Hochwälder, Jessica Sjövall, Lena Hjelte
Published by Open Journal of Nursing
http://file.scirp.org/Html/9-1440450_56445.htm

Depression And Cystic Fibrosis
By Vicki Thompson
Posted by Cystic Fibrosis Lifestyle Foundation (CFLF)
http://www.cflf.org/blog/depression-and-cystic-fibrosis-0

Prevalence and Impact of Depression in Cystic Fibrosis (November 2008)
By Alexandra L Quittner; David H Barker; Carolyn Snell; Mary E Grimley; Kristen Marciel; Ivette Cruz
http://www.medscape.com/viewarticle/584507

Taking Care of Me: Emotional Support
Posted by Johns Hopkins Cystic Fibrosis Center
http://www.hopkinscf.org/living-with-cf-teen/taking-care-of-me-teen/emotional-support-teen/

Teens, Cystic Fibrosis and Emotional Health
By Siri Vaeth, MSW and Lindsey Martins, MSW
Posted by The Cystic Fibrosis Center at Stanford
http://med.stanford.edu/cfcenter/teens/CysticFibrosisandEmotionalHealth_000.html

Local Resources

lo•cal re•sources

1 : pertaining to a city, town, or small district rather than an entire state or country

2 : a source of supply, support, or aid, especially one that can be readily drawn upon when needed

Emily Kramer-Golinkoff, 31

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Blooming Rose FOUNDATION FOR CYSTIC FIBROSIS

FC FOUNDATION CARE Your Full Service Cystic Fibrosis Pharmacy

Local Resources

Update #1
September 2016

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!

AIRWAY CLEARANCE

ASSISTANCE PROGRAMS

MEDICATIONS & TREATMENTS

NEBULIZERS

RESOURCE MATERIALS

SCHOLARSHIPS

LOCAL RESOURCES

NON-PROFITS

SOCIAL MEDIA

MENTAL HEALTH

FOUNDATION CARE
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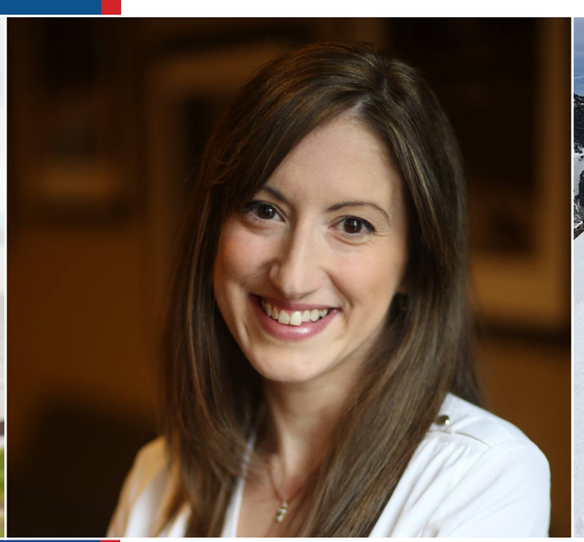

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