CF Roundtable
A NEWSLETTER FOR ADULTS WHO HAVE CYSTIC FIBROSIS
SPRING 2014

Three Tools To Help Maintain Mental Health

By Anonymous

My mind is a mess. I am constantly trying to clean it up and get it in order. I work and work and work. Sometimes it helps, and sometimes I can't get the dust out from under the bed or wash the dishes in the sink of my mind. I try to herd, prod and control my mind. I want to be happy and fulfilled and "live my best life," because I have an acute sense that time is short. I know that keeping my mind in shape will keep my body in the best shape. So I've been very persistent in trying to keep up my mental health. Along the way, I've discovered three main tools that have really helped me.

But before I describe my tools, I want to talk about what I am ultimately seeking in mental health. I am learning that the struggle to avoid, fix, or change uncomfortable feelings is futile, and not what I should focus on. According to Russ Harris, author of *"The Happiness Trap,"* pursuit of happiness and avoidance of pain will lead to frustration and anxiety. Any feeling of pleasure is wonderful, but we all know that happiness like that is fleeting. No matter how hard I try to hold on to a moment of happiness, it ultimately fades.

> "Trying to run away from pain and expecting to be happy all the time are the worst things I can do for myself because I set up a struggle that I never win."

The truth is that all life involves pain. We all grow old or get sick or have accidents and die. We all lose relationships to rejection, separation or death. As a cystic fibrosis adult, I've definitely had my share of that pain. But trying to run away from pain and expecting to be happy all the time are the worst things I can do for myself because I set up a struggle that I never win.

A better technique is to go deeper: to observe my thoughts and feelings and understand that I don't have to like them all. Instead, I must live with them. I can live through intense pain, fear, anger, sadness, futility. They fade just like happiness. They are part of my life. Instead of banging my head against the wall because I have bad feelings, I want to accept them and then make choices that will give my life meaning. By identifying and acting on the values that are important to me, I am planting seeds

Continued on page 15

INSIDE THIS ISSUE

CF ROUNDTABLE
FOUNDED 1990
Vol. XXIV, No. 2

CF Roundtable (ISSN 1057-4220) is published quarterly by the **United States Adult Cystic Fibrosis Association, Inc.** (USACFA), a totally independent, 501(c)(3) tax exempt, nonprofit corporation whose Board of Directors all have CF. Articles in *CF Roundtable* may be reprinted only with advance written permission from USACFA. All submissions to *CF Roundtable* become the property of USACFA and should include the author's full name, address and phone number. Submissions are subject to editing as needed and we reserve the right to edit any comments that disparage another person either by name or situation. Requests for anonymity will be honored.

CF Roundtable now is free for everyone. Tax-deductible donations are gratefully accepted to help defray the costs of printing, production and mailing of the newsletter as well as the costs of Website maintenance. Please subscribe online at: www.cfroundtable.com or by mailing in the subscription form at the back of this newsletter.

CF Roundtable does not give medical advice. Any medical opinions represented in these articles are those of the writer and do not represent the views of USACFA. We strongly suggest you consult your doctor regarding any medical references and before altering your medical regimen in any way. USACFA does not endorse any products or procedures.

United States Adult Cystic Fibrosis Assn., Inc.
PO Box 1618
Gresham, OR 97030-0519
Voice mail: 248-349-4553
E-mail: cfroundtable@usacfa.org
www.cfroundtable.com

EDITOR'S NOTES

I hope that spring is bursting out wherever you are. What a winter this has been. Let's hope we don't get a repeat of that weather any time soon. Come on spring!

We have some sad news to impart. **Kurt Robinson**, who was a Director of USACFA in the first decade of this century, has died. We offer our sympathies to all who loved him.

In our last issue, no one felt motivated to write on the Focus topic. This issue was the exact opposite. Many people wrote on the topic: "Maintaining Mental Health." In fact, so many people wrote that this issue is a whopping 44 pages!

The articles start on the front page where a writer, who wishes to remain anonymous, tells us of three tools she uses to overcome depression. Inside you will find more articles that continue the theme. **Lisa Cissell** writes of stresses that began with her diagnosis at age 25 and worsened when her younger sister became ill enough to be listed for lung transplant. **Andrea Eisenman** tells of dealing with worry and anxiety. She uses activity, Reiki and as few meds as possible to deal with it. **Paul Feld** writes of his concerns about the costs of his care and his worries of whether he is "worth" it. (He is!) **Jess Newport** tells of how yoga has helped her more than many meds. **Debra Radler** discusses how she compensates for the loss of some of her freedoms. **Laura Tillman** says her coping mechanism is to "Just deal with it!" I wrote of how laughter and favorite pastimes help me stay on an even keel.

James Chlebda, in "Creative Disengagement," tells how he uses his camera to help his mental balance. In "Coughing With A Smile," **Jennifer Hale** tells us how music, quotes and God help her. **Julie Desch** discusses depression and its connection to CF in "Wellness." She encourages people to talk with their docs about their anxieties or depression. In "Spirit Medicine," **Isabel Stenzel Byrnes** writes of using "mindfulness" to deal with negative emotions.

"Ask the Attorney" finds **Beth Sufian** answering questions regarding Social Security benefits and healthcare exchanges. In "Transplant Talk," **Susie Baldwin** shares her journey to lung transplant and the first eight months afterward. She will update us with more, later.

We introduce a new column in this issue. **Mark Manginelli** is a financial advisor who is sharing his expertise with us in "Protecting What Matters." He will focus on a specific topic, strategy or regulatory update that can have an effect on our community in one way or another.

Normally I write "Speeding Past 50," but in this issue we have a guest columnist, **Anne Williman,** who is a former Director of USACFA. She writes of her achievement of reaching 60 years of age. She offers some of the history of the "early" days of CF care.

As always, we hope that you will look at the upcoming Focus topics on page three to see if you want to write about any of them.

Stay healthy and happy.

Kathy

Publication of CF Roundtable is made possible by donations from our readers and grants from Sustaining Partners - AbbVie, Boomer Esiason Foundation, CF Services, Foundation Care, Gilead, Hill-Rom, and Vertex Pharmaceuticals, Inc.

MILESTONES

Please share the milestones in your life with our readers. Your successes and achievements may serve as a source of motivation for others in need of an infusion of "positive mental attitude" in the pursuit of their goals. Send us a note specifying your "milestone". Include your name, age, address and phone number. Mail to: ***CF Roundtable*, PO Box 1618, Gresham, OR 97030-0519. Or e-mail to: cfroundtable@usacfa.org**

ANNIVERSARIES

Birthday

Susie Baldwin
Los Angeles, CA
47 on April 10, 2014

Lisa Cissell
Bardstown, KY
51 on March 8, 2014

Tanya Cunningham
Sandy, OR
50 on March 6, 2014

Mike Darrar
Post Falls, ID
47 on August 25, 2013

Cynthia Dunafon
Staunton, VA
50 on February 2, 2014

Lori Morris-Hughes
Chesapeake, VA
50 on January 16, 2014

Kathy Russell
Gresham, OR
70 on April 17, 2014

Bob Tate
Streamwood, IL
49 on October 20, 2013

Wedding

Mike & Kathy Darrar
Post Falls, ID
23 years on August 11, 2013

Kathy & Paul Russell
Gresham, OR
49 years on March 27, 2014

Transplant

Susie Baldwin, 46
Los Angeles, CA
Bilateral lungs
1 year on December 22, 2013

Lisa Cissell, 51
Bardstown, KY
Bilateral lungs
3 years on April 16, 2014

Mike Darrar, 47
Post Falls, ID
Bilateral lungs
2 years on May 3, 2013

NEW BEGINNING

Cris Dopher, 42
Brooklyn, NY
Bilateral lungs
on December 10, 2013

LOOKING AHEAD

Please consider contributing to *CF Roundtable* by sharing some of the experiences of your life in writing. Read the **Focus** topics listed below and see if there are any about which you might like to write. In addition, humorous stories, articles on basic life experiences, short stories, artwork, cartoons and poetry are welcome. We require that all submissions be original and unpublished. With your submission, please include a recent photo of yourself as well as your name, address and telephone number. Photos will be returned. Send all submissions to: **CF Roundtable, PO Box 1618, Gresham, OR 97030-0519** or e-mail to: **cfroundtable@usacfa.org**

Spring (Current) 2014: Maintaining Mental Health.

Summer (August) 2014: Dealing With Conditions That Are Part Of CF. (Submissions due June 15, 2014.) Do you have CFRD, GERD, DIOS, CF-related arthritis, sinus disease, liver problems or any other CF-related conditions? How do you handle them?

Autumn (November) 2014: Dealing With The Death Of A Loved One With CF. (Submissions due September 15, 2014.) Have you had a spouse, sibling, child, parent or friend die from CF? How did that death affect you? How did you cope with the death? Do you have any suggestions to make it easier for others to handle?

Winter (February) 2015: Ways To Become A Parent When You Have CF. (Submissions due December 15, 2014.)

ASK THE ATTORNEY

Answers To Readers Questions

By Beth Sufian, J.D.

Many readers continue to ask questions related to Social Security benefits. In March we also had many questions related to the Affordable Care Act.

Nothing in this column is meant to be legal advice about a specific situation but is only information. If you have questions, please contact the CF Legal Information Hotline at: 1-800-622-0385 or at: CFLegal@sufianpassamano.com. All contacts are free and confidential. The Hotline is sponsored by a grant from the CF Foundation.

1. I have insurance right now so I do not need to purchase a plan on the Healthcare Exchange. If I lose my coverage in May 2014 can I then purchase a policy on the Healthcare Exchange?

Yes. The open enrollment period to purchase a policy on either the Federal Healthcare Exchange or a Healthcare Exchange offered by a specific state runs from October 1, 2013, to March 31, 2014. There are 16 states that operate their own Healthcare Exchanges, notably California, New York, Colorado and Kentucky. The state Healthcare Exchanges operate in the same manner as the Federal Healthcare Exchange but offer information and the ability to purchase a policy offered only in that specific state. While the Federal Healthcare Exchange had trouble when it initially launched, it is now fixed and easy to use both to view insurance coverage available in a certain area and to enroll in coverage.

If a person has health insurance on March 31, 2014, and loses that health insurance after March 31, 2014, the person will be allowed to purchase a policy on a Healthcare Exchange within a specified period after their insurance coverage ends. In addition, if a person has a change in income, change in family size or moves to another state, the person would be eligible to purchase a policy on the Healthcare Exchange after the open enrollment period ends on March 31, 2014.

However, if a person has no insurance coverage on March 31, 2014, and then decides to purchase an insurance policy on the Healthcare Exchange on April 1, 2014, he will not be able to purchase a policy because the open enrollment period has ended and he did not have insurance on March 31, 2014.

It is likely the next open enrollment period will be between October 1, 2014, and December 16, 2014, but the exact dates for open enrollment have not been announced.

A person can purchase a policy from an insurance broker or an insurance company at any time. However, the government subsidies that can help people with the premiums for monthly insurance policies are offered only for policies purchased through a Healthcare Exchange.

> *"After the first year a person [with a transplant]can still be eligible for SSA benefits as long as he/she can show that he/she is unable to work full time due to his/her medical condition."*

BETH SUFIAN

2. Has Social Security changed the medical criteria for a person with cystic fibrosis?

No. In February 2013 Social Security proposed changes to the medical criteria a person with CF must meet in order to be eligible for either SSI or Social Security Disability Insurance benefits. The CF community voiced its opposition to changes in the medical criteria by sending more than 20,000 letters to members of Congress about the changes. My column in the *Summer 2013* issue of this newsletter discussed the proposed changes at length.

Social Security acknowledged the outcry from people with CF and their healthcare providers in a national call in spring 2013 that allowed people with CF to ask questions about the

proposed changes. However, there has been no indication from SSA about changes to the proposed criteria published in February 2013. It is possible SSA made some changes to the proposed criteria, but there is no way to know if changes were made based on suggestions from the CF community.

At some point in the second half of 2013, the Social Security Administration submitted proposed changes to the CF medical criteria to the Office of Management and Budget (OMB). OMB must approve any changes to the SSA medical criteria. The Social Security Administration has estimated that OMB will make a decision on the proposed CF medical criteria in July 2014. Once the OMB decision is released, there will be a 30-day period that must expire before the new criteria become effective.

If an application for benefits is pending at the time the new criteria are effective, then SSA will use the new criteria to determine eligibility for benefits. If a person has benefits at the time the new criteria are implemented and has his/her benefit eligibility reviewed, then the new medical criteria will be used if the person has had "minimal medical improvement" in his/her health. If there has not been minimum medical improvement then the criteria in effect at the time the person started receiving benefits will be used to determine continuing medical eligibility.

It is unlikely SSA will immediately review all individuals who already receive SSA benefits to see if an individual meets the new medical criteria. Other advocacy groups for people with chronic medical conditions have had SSA medical criteria changed in recent years. Those groups report that individuals who work part time are the first to have their SSA benefit eligibility reviewed once new medical criteria go into effect. There is no way of knowing if this will happen if/when new CF medical criteria are implemented.

The *CF Roundtable* blog will post the final SSA regulation regarding SSA medical criteria on the day it is released by the Social Security Administration. If you are interested in learning about the new criteria please make sure you are signed up to receive e-mail notification of new blog postings.

3. Is there a one-year limit for Social Security benefits for a person with CF who has received a lung transplant?

The CF Legal Information Hotline has received a large number of questions asking if there is limit on SSA benefits for those who have been transplanted. There have been incorrect postings on CF-related social media sites about SSA benefit eligibility post-transplant.

Section 3.11 of the Social Security Listing states:

Lung transplant: Consider under a disability for 12 months following the date of surgery, thereafter evaluate the residual impairment.

Section 3.11 does NOT mean a person is considered disabled and eligible for benefits for only one year post lung transplant. This section of the SSA medical eligibility criteria means that during the first year the person is post-transplant, Social Security presumes the person is disabled. After the first year a person can still be eligible for SSA benefits as long as he/she can show that he/she is unable to work full time due to his/her medical condition.

Typically a person has SSA benefit eligibility reviewed three to five years after being approved for SSA benefits. If a person works part time then, sometimes, SSA reviews benefit eligibility sooner.

Full-time work activity is defined by SSA as making more than $1,070 from work activity in one month. In addition, a person who works more than 15-20 hours a week, no matter what amount of pay is received from that work, may be considered able to work full time by SSA.

A person with CF who is three years post-transplant may have his/her Social Security benefit eligibility reviewed by Social Security. The person will need to supply medical evidence that supports a finding that health issues keep the person from returning to full-time work activity. The person may have numerous doctors' appointments during the week, or may have issues with fatigue, or significant digestive or sinus issues that prevent him/her from working. In addition, some transplant physicians do not want their patients working in jobs that expose the transplant recipient to members of the public on a daily basis due to their immuno-suppressed status.

A person who has been transplanted must have medical evidence documenting the medical issues that prevent the person from working full time. Some people who are post-transplant do not visit the doctor as often as they did before their transplants. If medical eligibility is reviewed by SSA, it is much more difficult to continue benefits if there is very little medical evidence documenting the issues the person faces on a daily basis that prevent him/her from working.

Beth is 47 and has CF. She is an attorney who specializes in disability law and she is a Director of USACFA. Her contact information is on page 2. You may contact her with your legal questions about CF-related issues.

SPIRIT MEDICINE

The Art Of The +/- Balance

By Isabel Stenzel Byrnes

"There is, finally, only one thing required of us: that is, to take life whole, the sunlight and shadows together; to live the life that is given us with courage and humor and truth. We have such a little moment out of the vastness of time for all our wondering and loving. Therefore let there be no half-heartedness; rather, let the soul be ardent in its pain, in its yearning, in its praise. Then shall peace unfold our days, and glory shall not fade from our lives."

–Rev. Kendyl Gibbons

The idea for this article came from a random memory that popped into my mind the other day. I remember attending one of the earlier CFRI educational conferences in the late 1990s. This was a difficult time for my sister, Ana, who was getting listed for a lung transplant, was on oxygen and was very fragile. Ana and I were sitting in a large room with more than 30 CF adults during the designated support group time. We went around the room to check in. Ana poured her heart out about how miserable she was, how scared she was, how unfair this all was. Across the circle, a much older gentleman with CF responded, gently, with the best of intentions, "You just have to be positive." My broken-spirited sister deflated even more. Back in the hotel room, I heard a mouthful from Ana about how no person twice her age with CF had the right to tell her to be positive.

Nowadays, positive thinking is all the rage. Our media, health education and pop psychology are full of messages about the importance of positive thinking. Numerous academic centers have invested in research on the "neuroscience of happiness." For example, the largest class ever recorded in Harvard's history was a class on "positive psychology." We've often heard that positive thinking and the relative absence of negative thinking can benefit mental health. Most of us, unconsciously or consciously, on a daily basis or as a lifelong quest, strive to eliminate negative emotion and expand positive emotion.

As a CF patient, I have often felt pressure from my healthcare providers to remain positive. The smiling, cheerful patient who sails through adversity attracts tender loving care and is often called "amazing" and "inspirational." But Pollyanna people irritate me. I fully admit that I'm drawn to friends with CF who are healthy copers – those who are generally hopeful, optimistic and have some deeper sense of what their struggle is all about … yet are also able to express frustration and able to poke cynically at our CF drama. When I encounter someone with CF who complains heavily, plays the victim role or remains resentful or angry, it takes a lot of energy out of me. Positive thinkers are easier to deal with.

ISABEL STENZEL BYRNES

The trends of CF research have promoted a culture of hope and positive thinking in the CF community. Much of this is genuinely warranted, as people are living longer and better, and treatments like Kalydeco® are having profound benefits to some. However, I need not even state the obvious: that life with CF is not always positive. The more we push positive thinking, the less permission we have to acknowledge the suffering that our CF causes. Living with CF offers opportunity for the full range of positive emotions – great joy, bellyaching and cough-inducing laughter, immense love and connection, and growth and transcendence. But living with CF also invites plenty of opportunity to experience negative emotions such as anger, resentment, shame, despair, envy, bitterness, hopelessness, isolation. This is a messy disease. This emotional and physical roller coaster invites all of these feelings. Like waves in an ocean, they come and go, and come back and go again. Most of us with CF have been caught up in negative emotion at one time or another; some of us have become unbalanced or stuck in this negativity for longer periods.

We all have choices with our emotional soup that we are swimming in. We can vent and cathart our frustrations and distresses. We can convert negative emotion into a defense mechanism. But Nancy Reeves, Ph.D., warns us about negative emotions. She calls negative emotions "expensive emotions" because they cost a great deal of time and energy. They also "give the illusion of power, which pushes [the holder of such emotion] to violence of thought, word or action." They narrow our view of the world and she warns, "those who believe expensive emotions are protective use so much energy in these defenses that there is little or none for life enhancement." An example of this might be feeling angry at a doctor for saying something that threatens our sense of hope. Anger might give us power over the doctor, knowing that he/she is wrong, while we are right. But holding a grudge is exhausting. Many of us with CF don't have energy to spare for expensive emotions. Another way to look at this example is to wonder why the doctor said what he/she said, and why we reacted so strongly.

Though negative emotions use up a lot of energy, they serve a very important function. Negative emotions typically present themselves as our first gut or instinctual reaction towards something that happens to us, good or bad. Let's not forget that we humans are hard-wired to be negative. Imagine this: our prehistoric ancestors who lived on the savannah heard a rustle in the bushes. Did they immediately think it was a cute family of quails settling in their nest? No! They immediately thought it was probably a saber-toothed tiger about to attack them. This negativity bias that evolved in our brains was a survival advantage. Our fear, doubt, despair, suspicion have a purpose. They serve to warn us to do something, to protect ourselves.

For example, when I have a chest pain, or I get unusually breathless going up stairs, I think I have pneumonia or I'm going into rejection. Then I call my doctor or exercise more. Our fears and negative thoughts serve to help us check in, assess and attend to something that is bothering us. To not heed to our negative emotions is to become complacent. Also, negative emotions are a warning call for those around us. If we're having a hard time, and we're courageous enough to share it with others, we will draw in a compassionate circle of social support that we need to get through a tough time.

> *"Avoiding negative emotions has real disadvantages. It limits our lives drastically, since most scenarios in life involve some uncomfortable emotions."*

Negative emotions help us evaluate our experiences. How often have you felt really low, but when the feelings pass, you can say something like, "That was a tough time, but I'm doing better now." Similarly, in the depths of despair, we can think, "This is horrible. I hope it gets better." Through negativity, we glimpse hope, we gain clarity.

In the CF world, negative emotions have the potential to mobilize and motivate us to do something to control CF. I know a mother of two daughters with CF who organizes a large fundraiser every year to raise money for CF. At one gala, she spoke loudly into the microphone, "I do this because I'm angry. I'm angry there isn't a cure yet for CF." Her emotion was palpable throughout the audience. Sometimes our negative emotions keep us going – they fuel an energy that keeps us from collapsing.

Psychologists and neuroscientists have shown over and over that being positive helps people develop an enhanced quality of life, contentment, personal growth and awareness. If we reframe a negative situation to a positive light, then we should be able to be happier, right? Well, reframing a situation could be an important coping mechanism. However, it can also mean we are ashamed of or feel guilty about our negative reactions, or worse yet, we are avoiding to really *feel* a negative emotion. Avoiding negative emotions has real disadvantages. It limits our lives drastically, since most scenarios in life involve some uncomfortable emotions. Avoiding negative emotions is also futile. Telling yourself that a certain emotion is intolerable or dangerous traps you in constant vigilance regarding the very thing you're trying to avoid. Psychologists call this paradoxical thought suppression – the more you try *not* to think about sadness, for example, the more you'll think about sadness! Emotional avoidance often involves denying the truth – also not a very healthy foundation for a happy life. In fact, suppressing or hiding negative emotions has been shown to be bad for our *physical* health. In his studies on expressive narrative writing, Dr. James Pennebaker found that suppression of thoughts and feelings is associated with sympathetic

Continued on page 11

SPEEDING PAST 50...

Sixty And Counting

By Anne Williman

Last spring, I reached a huge milestone for me – I hit 60 years old. Yeah, I know that's still young – or at least middle-aged for most. But when you have cystic fibrosis, hitting that age is pretty amazing. For all you young things out there, let me introduce you to the world of a Senior Cystic (thanks to Julie Desch for the term!).

During my first few years of life, back in the dark ages, my parents knew something was wrong. My lungs were fine, but I just didn't grow. The doctors they took me to thought it was allergies or some other stomach ailment. Finally when I was five and we were living in Indianapolis, someone had the bright idea to test me for CF.

Sweat tests were a little different back then. I was stuck in a plastic bag from the neck down and lay there for hours, letting the sweat collect. I remember my mother reading *The Little House on the Prairie* to me as we waited.

After the required number of hours, the nurse told my mother I could get dressed and go. Unfortunately, it was a cold day. Mom questioned the wisdom of sending a sweaty child out into the weather, but the nurse assured her it was okay. So off we went.

Next thing I knew, I had pneumonia and was back at the hospital, this time as a patient. Mom was always convinced that sending me out in the cold without giving my body time to cool off was to blame.

There was an oxygen tent draped over the head of my bed, and I remember cramming my entire body into it when they came to give me a shot.

I got over the pneumonia, but the sweat test resulted in a diagnosis that wasn't going to change. I had CF. At that time, the doctor could tell my parents only that I wouldn't live to reach the age of 10. He gave them digestive enzymes for me and told them to try to give me a happy, though short, life.

Of course, my parents were devastated. But they were people of faith and weren't willing to give up. Shortly afterwards, we moved to Columbus, Ohio, and they heard about a doctor in Cleveland who was trying different things with CF patients. Many of their new friends in the CF parent support group weren't interested. (All of their children later died from the disease.) But Mom and Dad drove the two hours to see Dr. LeRoy Matthews at the Rainbow Babies and Children's Hospital. I liked him – he was a kindly, soft-spoken man who seemed to really care about me.

> *"The night before our engagement party, my mother took Jon aside and spelled out the realities of CF. "You will not have a long marriage," she told him."*

But suddenly I was living a different life that included postural drainage, where my lungs were pounded by hand several times a day while I lay head down on a tilted table. I had to sleep in a mist tent at night, which covered the top of my bed and left me with wet hair every morning. And of course there were all the pills, nebs and trips to see the doctor every six weeks

I had a rough year for first grade. I missed two-thirds of the days of school due to illness, and there was talk of making me repeat the grade. But Mom worked with me at home and I was able to go on to second grade.

The years passed and my life was pretty normal, in spite of all the CF treatment I received. I was starting to have issues with my lungs but nothing bad enough to be hospitalized. There were birthday parties, proms, a driver's license and, finally, graduation.

I decided to attend a private college several hours from home, which meant I would shoulder the whole burden of CF. But I was ready for that. We found a student at my college who was studying to be a physical therapist and hired her to do my postural drainage each day. Amazingly, she was from Cleveland and was able to go to the hospital there to get trained how to do it. We moved the tilt table into the dorm basement and met every day.

I brought my mist tent, too, and every few days had to clean the equipment that produced the mist. That meant washing it all and running white vinegar through it. My roommate couldn't stand the strong vinegar odor and insisted that I stick the hose that was pouring white steam out of the window. I wonder what people driving by the dorm thought when they saw the steam?

College life was great and the best part was meeting Jon. We decided to get married the summer after my

junior year. The night before our engagement party, my mother took Jon aside and spelled out the realities of CF. "You will not have a long marriage," she told him.

But Jon was ready to go ahead anyway. The wedding took place and I started my senior year of college. Sometime that spring, I was suddenly struck with the understanding that I had a fatal disease and would not live to see middle age. It greatly troubled me, but after thinking and praying a lot about it, I was able to accept that my life was in God's hands and He would keep me until it was my time to go. Little did I know that 40 years later, I would still be here!

After a few years, Jon and I decided we were ready for children. Back then, I was told a pregnancy would be very bad for me and we went with adoption. We were placed with a sweet little baby girl whom we named Amy. She was perfect.

When she was about three, the day finally came when I had to be admitted to the hospital for two weeks for a clean-out. I was 29 and it was my first time. I was two hours from home and had never been away from Amy for overnight. It was horrible.

Back in the day, CF was a children's disease. So I was in a children's hospital, even at my age. As Jon, Amy and I walked out upon my discharge, the receptionist smiled sweetly at us. "I bet you're glad to be taking your little girl home," she gushed. Jon and I glanced at each other. Then we smiled at her and kept walking. She didn't need to know that I had been the patient.

At some point, it was determined that the mist tent was not helpful and I no longer had to put up with it. (Jon was delighted!) But we still did the postural drainage every night. Amy had watched from her baby swing at first. Later, she came over to us as Jon pounded away, cupped her little hands and "pounded" my chest too.

The years passed. We adopted two more babies, both boys, and life went on in a blur of laundry, sports, school, ballet lessons and church. I worked part-time as a freelance writer, selling more than 700 magazine articles and three books. We traveled to many states as well as took trips to countries such as Brazil, England and Israel. And yes, there was always CF.

As I aged, there were complications: GERD, osteoporosis, CF-related diabetes and lowering lung function. That meant more hospital stays (finally in an adult hospital), more drugs, more treatments. It affected the kids, too. More than once, they asked Jon, "Is Mom dying?" But somehow, I always pulled through.

So that takes me up to now. My children are all grown, married and with kids of their own. Things have come full circle – the other day my two-year-old grandson watched Grandpa pounding on Grandma and cupped his little hands and "pounded" on me too. (Yes, I have a Vest, but I like the postural drainage better.)

Though I have lost a lot of lung function and strength, I am still here. The future of CF looks brighter than it ever has, although I do remember my mother telling me when I was a teen that we were on the edge of a breakthrough for CF back then. Now, it appears that's really happening.

I do believe that younger people with CF have every reason in the world to think they will live to reach 60 and beyond. If I can do it, it's possible!

Anne is 60 and has CF. She and Jon live in Middletown, OH.

YOU CANNOT FAIL

The **You Cannot Fail** program is based on a saying that Jerry Cahill's parents shared with him at a very young age. This saying helped keep him determined to push through all bumps along his path.

You Cannot Fail is an inspirational launch pad that empowers people to discover and embrace their inner hero; to face the challenges of life with strength and courage; to meet each day with optimism; to live a life of creativity, purpose, and passion. **You Cannot Fail** collects, organizes, and shares individual's stories about specific aspects of their lives in order to motivate and inspire others to be the heroes of their own stories.

Visit: www.youcannotfail.com to share your story, inspire others, and to become a part of this official program of the Boomer Esiason Foundation.

PROTECTING WHAT MATTERS

Financial Planning with Cystic Fibrosis

NEW COLUMN

By Mark Manginelli

If there's one thing that's for sure, living with cystic fibrosis (CF) or even caring for someone with it, is certainly no easy task. Aside from the emotional, physical and mental struggles a chronic illness can add to a family's daily routine, there are significant financial challenges that they must face. Everyone reading this already knows firsthand just how financially debilitating CF truly is.

I've learned a great deal through my personal experience of living with CF – from my own encounters as well as those my brother, who also has CF, has experienced. One of the most pertinent lessons has been the vast magnitude of planning we must do, which is often far broader than that of the average person. At any given time, our world can be turned upside down. It's absolutely vital to assure that we have a well-structured strategy in place and, moreover, one that provides us the ability to handle any and all directions life may lead us in the most efficient manner possible.

As I look back at the progress made over the past 20 years and consider what that means for those living with CF, it truly amazes me. Advances in medicine have allowed for drastic changes in the future outlook for those with CF and now, with more adults than children living with CF, it's clear that we must begin planning to live fuller, more normal lives. My hopes for this column are to deliver an unbiased, educational perspective on the numerous topics and concerns pertaining to life with CF, drawing both from my personal experiences as well as stories of my clients with chronic illness or special needs with whom I work on a daily basis. I firmly believe it's no coincidence I have been diagnosed with this disease while also choosing my path as a comprehensive financial planner. I find myself in a unique position; fortunately, my clean bill of health at this point in my life allows me to take on this role, but my career path also allows me to see this industry in an impartial light.

The financial services industry is laden with misinformation. It is an industry that has been defined with confusing and often unnecessary products that greedy brokers sell and, in recent years, blockbuster movies depict how people are ripped off for millions, if not billions, of dollars. (Read: *The Wolf of Wall Street* or Bernie Madoff.) The industry as a whole is still trying to ice its black eyes, but the general perception often leaves a sour taste of disbelief or distrust in the mouths of most people.

> *"We all have our own unique issues, concerns, struggles and desires and that should be reflected in our financial planning."*

MARK MANGINELLI

I've had the pleasure to work for firms that conduct business according to a high moral code, but possibly more beneficial has been the insight I've gained into the inner workings of the stereotypical money-hungry, commission-driven firms that, sadly, still exist in abundance. Unfortunately, I've met countless individuals who refer to themselves as "advisors," yet consistently run their practice by figuring out how to sell their clients proprietary investments, insurance products or other cookie-cutter models. What I've seen far too little of, however, are *true advisors* whose actions are a genuine representation of their words. What this community of ours knows all too well is that we're not like everyone else; we all have our own unique issues, concerns, struggles and desires and that should be reflected in our financial planning.

Each article will be focusing on a specific topic, strategy or regulatory update that can have an effect on our

community in one way or another. It would be helpful to understand the most popular concerns the community faces in this area as a whole and some of the key areas about which people may want to know more. Some of the likely concerns and potential future topics of conversation that come to mind include:

- Have I properly coordinated my social, medical, financial and legal strategies to work efficiently with one another?
- How can I qualify for life insurance or disability insurance and are there companies out there willing to give it to me?
- Are my estate documents (wills, trusts, guardians, power of attorney, etc.) drafted correctly and will they do what I intend for them to do? Have I properly identified all of the financial resources I have available and are they positioned for success during and after my life?
- What government benefits are out there and how do I protect my ability to receive them in the future?
- How do I fund the rising costs of long-term care?

A few more specific topics that my clients, including my own parents, often express interest in are:

- How do I save for my own retirement and plan for the loved ones I leave behind with an unknown life expectancy?

Furthermore, if I leave behind money:

- Is it structured properly so I don't lose 50% or more to taxes and fees?
- Is it risking my children's ability to receive government benefits in the future?

I hope this brief column has sparked everyone's mind to consider their family's plans, or lack thereof, and whether it's time to evaluate them. I am very excited to have this opportunity to share my knowledge with this community that helped raise me and to be a resource for anyone who has specific questions. Enjoy the spring season, but keep those dreaded allergies as far away as possible!

Mark is 28 and has CF. He lives in Edison, NJ. You may contact him at:mmanginelli@usacfa.org.

BYRNES *continued from page 7*

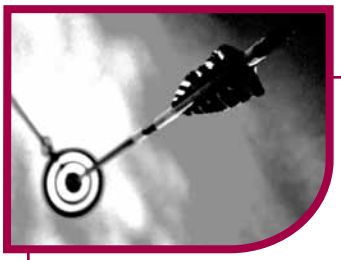
arousal (fight or flight), including hypertension, increased heart rate and respiration, vasoconstriction and all the other usual effects of stress. The opposite of avoidance is acceptance. Acceptance of our experience is associated with self-acceptance and physiological homeostasis. In other words, acceptance of our range of thoughts and feelings reduces stress.

Dr. Pennebaker's studies found that it's really important for us to create a balanced view of our positive and negative life experiences. He found that writing only about their negative experiences led people to rumination, stagnation and depression. People who wrote only about positive experience did not experience psychological healing (probably because they weren't authentic). Writing about a difficult emotion, and then adding some interpretation and sense of meaning, led to improvements in mental health. That's like saying, "I hate CF, and it's really hard sometimes, but it brought me closer to my family and taught me what a strong person I am." In other words, people who take the good and the bad together may detoxify the bad experiences, allowing them to make meaning out of them in a way that supports psychological well-being.

> *"Our fears and negative thoughts serve to help us check in, assess and attend to something that is bothering us."*

On a spiritual level, denying negative emotions is denying our humanity. How can we suppress negative feelings when even some of our higher powers had negative feelings? For example, the Bible is full of references to God's wrath. "Jesus wept" (Gospel of John, chapter 11, verse 35) is the shortest verse in the Bible and pertains to Jesus's sadness when he learns that Lazarus has died. But these two words reveal a critical reminder: that Jesus Christ was a real man with human emotions and reactions. In addition, even Prince Siddhartha became frustrated, despairing and increasingly disenchanted with the stark realities of human suffering before embarking on his quest to reach enlightenment through Buddhahood. As spiritual creatures, our human hearts, minds and spirits have the right to experience the full range of human emotion.

Continued on page 41



FOCUS TOPIC

MAINTAINING MENTAL HEALTH

Keeping My Balance

By Kathy Russell

What a winter this has been! I believe that most of the country suffered during this winter. Oh, how I love spring. Warmer weather and blooming flowers are so much easier to handle than ice and cold. With spring comes the promise of another season of growth. That is so important to me and to my mental health. I feel in much better balance, when the weather is warmer.

In an effort to avoid seasonal affective disorder (SAD), I have daylight-style lamps in my house. I spend a lot of time each day by large windows that look out upon a yard that is filled with trees. The trees are filled with birds and squirrels, among other forms of life, which keep me amused with their antics. If I feel like it, I can sit and watch the great outdoors for hours at a time.

One of the things that can cause many of us to feel great unease is our insurance coverage. Even though we may have a policy that says, on paper, that we are entitled to certain coverage, when it comes right down to it, there may be someone who is bound and determined that we will not get that coverage. The energy that it takes to make sure that we get what we paid for may be most of our reserve energy. If the battle is too long fought or too hard fought, we may end up getting ill. At the very least, we may end up with a doozy of a headache.

I am very fortunate because my husband manages all of my insurance needs. He is the one who spends long periods of time, sometimes as much as hours, on the phone with providers to make sure that everything is done properly. He also handles the ordering of my prescription meds. He keeps everything up-to-date. Since I started handling my own medical needs when I was in my latter teens, I feel that I can let him do the wrangling now. And, sadly, there is a lot of wrangling to do. One would hope that medical insurance questions could be handled fairly easily. That just isn't the case.

KATHY RUSSELL WORKS ON HER FAVORITE JIGSAW PUZZLE.

> "Now I am happy just to be able to wake up, get out of bed without too much pain, get dressed and meet the world."

Since Paul, my husband, is my advocate with all things medical, I don't have to expend precious energy or experience any mental unease about these things. I am so fortunate to have this arrangement. I know that it gives him headaches, at times! So that is one way that Paul helps me maintain my mental health.

Paul helps my mental health in another very important way. He makes me laugh. You may not realize the importance of laughter to one's well-being. Laughing increases the release of endorphins, which are the body's natural feel-good chemicals. The actual act of laughing causes this increase. We are better able to tolerate pain and irritation after a good laugh. That's why laughing until it hurts feels so good. I have written before of how having Paul relate a funny story to me, when I was in pain, enabled me to overcome the pain and do without pain medicine. If you've never experienced this effect, give it a try. You might learn something about yourself and you will get a good laugh out of it, at the very least. We all know that a good laugh can cause a really good episode of airway clearance. That is also a good product of laughter.

Having known and understood, since I was 12, that I have a disease that could shorten my life gave me a different perspective on life from that of most of my peers. My friends would take all sorts of risks that I was reluctant to try. I didn't want to "push my luck." I wasn't interested in smoking (anything), or drinking to stupidity, jumping off of cliffs or racing cars on city streets. (Didn't mind racing on the pavement at the old shipyards, however.) I figured that just getting through life was challenge enough for me. I

didn't want to live like a cloistered nun, but I did try to live carefully. I don't feel that I missed out on anything terrific.

Now I am happy just to be able to wake up, get out of bed without too much pain, get dressed and meet the world. As many of my friends who are my age or older say, "Every day that we're on this side of the grass is a good one!" As we age, we realize how short our lives are becoming. We know that people of our various ages die. We know that each time we say, "Good bye," may be our last time to see that person. It gives us permission to express our love and caring for each other. I like that and it does help to ease the pain of loss that I experience each time another friend dies. That helps me maintain my mental balance.

I used to use books to help me maintain balance, but I am having more trouble reading now. I hope that will be better after I have my cataracts removed, later this year. Until then, I use colorful jigsaw puzzles to cheer me. There is one that I do over and over. It has a lovely blue sky with fluffy white clouds. There are two, vivid rainbows across the sky. There are animals in the grass and a stream running through the lower portion of the picture. Every time that I work that puzzle, I feel happy. I am transported to fresh air, sunshine and a babbling brook. Ah, what tranquility. I love it.

I wish such tranquility for you. As I reach 70 years of age, I realize how short life is and how wonderful it is. My life may not be exactly as I thought it would be, but it has been a great life so far. Now, if I can just continue to maintain my balance.

Kathy is 70 and has CF. She lives in Gresham, Oregon, with her husband, Paul. You may contact her at: krussell@usacfa.org.

Coping With The Ups And Downs Of Life

By Lisa Cissell

Since I wasn't diagnosed with CF until age 25, most of my worries growing up were part of a fairly normal childhood. As a young girl, it was worrying whether there was a monster in the closet or under the bed and then, as I got older, it was school tests, boys, clothes, etc. I have always had a fairly positive attitude; so most issues were easily managed.

However, my levels of stress and anxiety increased once I received the CF diagnosis. Finding out that I had a chronic, incurable disease took a very long time to process. I think my best method of dealing at that time was denial. I had few symptoms, so why not pretend everything was okay? I told very few people. It was not a healthy way to deal with the situation, but that is where I found myself for the first 10 years of knowing I had CF.

Now, fast-forward to mid-1998 when my younger sister Mindy's health began to decline and she was listed for a lung transplant. My whole family was confident she would receive one, so it was a total shock when she passed away in January 1999. The grief that followed was overwhelming, and I felt as though I was in a fog for months. I eventually sought help from my CF clinic's psychologist, and with regular visits, I was finally able to let go of some of the anger, sadness and guilt. It was at that time I also started taking a low dose of the antidepressant Zoloft. I have continued to take this medication and it seems to have helped me with no evident side effects.

Another way I tried to combat my depression at that time was to reach out to others with CF. Other than my sisters, I really didn't know anyone else with CF. I had been receiving and reading *CF Roundtable* for years and found it very helpful and informative. In an issue in 2000, I saw information about a retreat for CF adults and teens that was sponsored by Cystic Fibrosis Research, Inc. (CFRI), in California. I knew I had to go and it was a definite turning point in my life. Having these friends in my life has added even more diversity to my support system, and communicating with them was especially important as I went through the experience of my lung transplant in 2011.

LISA CISSELL WITH HER DOG, SHERMAN.

Since receiving my transplant, I am able to exercise much more than before. I do jazzercise on a regular basis and have started running recently. I find that both are beneficial to my mental state; the jazzercise appeals to my love of dancing and good music and the running puts my mind in a peaceful place. Exercising also gives me such a sense of gratitude for my lung donor.

Another coping strategy I have for getting through the rough times is to incorporate as much fun and laughter into my life as I can. I love sarcasm, wit and humor, whether it comes from conversations with my friends, viewing silly Websites or watching a good comedic TV show or movie. For me, laughter has been an extremely healing medicine.

Finally, on those days when I am low and want to do nothing more than lounge in the recliner, I turn to my pets. My dog, Sherman, is such a cuddly little fellow and he has been such a comfort to me. My kitty, Copper, is a typical cat and more aloof, but he has his affectionate moments, too. Animals in general really lift my spirits and just watching a few cute puppy or kitten videos online can usually bring my stress level way down.

Overall, I think I do a fairly decent job keeping my mental health in a stable place. As I have described, it has taken a combination of many factors and interests to keep my mind in a positive place.

Lisa is 51 and has CF. She is a Director of USACFA. Her contact information is on page 2.

that lead to a more sustainable happiness: the knowledge that I have lived well.

Now, on to my tools. My issue is depression, and I don't think I'm alone among CF adults. Depression is one of the most common complications of chronic illness. My (and our) burden is the never-ending onslaught of CF living. And to top it off, we are regular people with problems that have nothing to do with CF, like bad relationships.

My first tool is antidepressant medication. I began taking Zoloft 17 years ago, when I was 21 and my health nose-dived when I was in the middle of college. I couldn't see my way through the difficulty, pain, fear and hopelessness, and so I found a psychiatrist. Zoloft immediately lifted my mood and gave me a sense of well-being that I hadn't had before. It carried me through my declining lung function, diabetes diagnosis, sinus surgery and lung transplant. I was not happy, per se, during that time, but I was able to fight and cope.

Through the years, I've had several psychiatrists and medication changes, and I am currently taking three meds right now. Soon after my lung transplant, when I was feeling a great sense of renewal and hope, I wanted to see how I would do without an anti-depressant. I recall having a complete meltdown – over losing the batteries to my insulin pump – and scaring my family. I just couldn't handle the day-to-day challenges. I have come to terms with the fact that I need anti-depressants. And I've also learned that it is important to continue seeing a psychiatrist to keep on top of the medication adjustments. Just receiving a prescription from my CF doctor to continue previous meds did not work after a while.

Second, I work on issues in counseling that help me take concrete steps toward making my life better. I've had many counselors over the years, and each counselor has his or her own style and technique. I've found that the most important factor in whether a counselor helps is whether he or she simply "gets me." It's not easy to find, and it's a bit of trial and error, especially when insurance changes and I need to start all over with someone new. It might seem like being in such a safe space would lead to complete honesty, but I've found that I need to dig deep and be honest with myself to get the most benefit.

My third tool is exercise. I'm just not the same without it. I try to exercise at least five times a week. It lifts my mood and gives me a sense of accomplishment, even if I've done nothing else in a day. Truth be told, I don't really like exercise, and I'm not athletic, but the feeling of being finished with exercise is so phenomenal that I keep at it.

That's how I live inside my crazy, turbulent, thrashing mind these days. I wish everyone the best of luck inside their own brains.

The author is 38 and has CF. She lives in California. You may contact her through us at: cfroundtable@usacfa.org.

Pay It Forward

Again, our readers continue to amaze us. Our first fundraising campaign continues on-beyond our expectations! We are overwhelmed by your generosity and support of our efforts to make *CF Roundtable* available for free. We thank you for your continuing endorsement of our endeavor.

Below is a list of those who continue to "pay it forward":

Laura Tillman
President

Bridget Barnes
Kevin Corr
Donald & Suzanne Davison (in honor of our son, David W. Davison)
Paul Feld (in memory of Ana Stenzel)
Hilda K. Garlock
Thomas & Mary Holmes
Abby Huntington
Dave & Sue Keon (in honor of Erin Keon)
Glen & Rhonda Keysor
Gay Kay Lazur
David & Julie Lewis (in honor of David Lewis)
Med Systems
Modern Health Specialty (PX), LLC
Jim & Carol O'Brien (in memory of our son, Ken)
Sonya Ostensen (in honor of Sophie)
Dan Seilheimer MD (in honor of Paul Quinton Ph.D. and Beth Sufian J.D.)
Phyliss Sewell
Deb Stalling
Robert Tate
Helen Young

The Coping Skills Of A Compensating Mind

By Debra Radler

I used to think of it as being handed a sentence. The late 1960s were not exactly cutting edge years for CF scientific breakthroughs, and the word on the medical street was that this was an incurable, progressive disease with a very grim future – a short one! I can still remember, as a seven-year-old, sitting in the doctor's office with my mother and having it explained to us. It definitely felt like a sentence to me. And just as the convicted felon feels when he first enters his cell, I also felt a bit doomed.

But we've all heard stories of prisoners who are locked in tiny cells for most of their lives and still find ways to evolve and find purpose. It's mind over matter. It is knowing that your ultimate fate is determined more by your tenacity than by the obstacles that befall you or the freedoms that are taken from you.

DEBRA RADLER AT VICKSBURG NATIONAL MILITARY PARK, VICKSBURG, TN.

Cystic fibrosis has taken certain freedoms from me, unquestionably. The freedom to exchange air the way I once did, the freedom to travel lightly, the freedom to skip an occasional treatment without suffering. These are freedoms that I miss. And in the next ten years there will be those freedoms that I enjoy today that will also be taken from me. It's inevitable.

So how do I cope? How have I coped? Have I really coped? Depending on the particular decade of my life, these questions would be answered very differently. In my first three decades I coped with the fears of my inevitable decline through constant movement, almost like a subconscious fight or flight response. I was never, ever content to be at rest; and no matter where I was in my life, I wanted to be somewhere else. I dabbled in many different activities and relationships. I

Mailbox

Tomorrow my partner, Tyson, and I are going to commission an engagement ring at a jeweler in town. We've been together six years and now that he's bought a house for us, it's time to get engaged. The house has had and still needs a lot of work before we can move in. We're hoping it will be in live-in condition by Thanksgiving, which is when we'll probably have a very small wedding. I credit *CF Roundtable* for these events; reading about various people in the newsletter who met others and got married made me realize that this was possible. I also encountered people through *CF Roundtable* who were on chat lines, and it was revolutionary for me to talk to others with CF who were married. Thanks for all your good work.

Darleen Boynton
Ann Arbor, MI

Love this publication! Keep up the good work!

Dave & Sue Keon
Farmington Hills, MI

Thank you for the valuable perspectives you provide. From the appreciative mother of a 32-year-old with CF.

Abby Huntington
Narberth, PA

I sent my donation in honor of Sophie who is five. May she thrive to adulthood and beyond. I hope this newsletter helps her someday as it has me. I am 38 and have CF. I just became a new mom to a healthy baby, Maislyn Lona, which was a miracle! I love *CF Roundtable!* It has helped me with all sorts of information on different issues that we face every day.

Sonya Ostensen
Inverness, FL

Thank you for all you do.

Gay Kay Lazur
Tierra Verde, FL

convinced myself that this disease would not interfere with my life, when, in fact, it was the driving undercurrent to my every decision and action.

In the next two decades I coped with the many colors of this disease through the help of one particularly wise therapist and some much-needed maturity. I can honestly say that I'm far more mentally healthy today than I have been at any other point in my life. I've calmed down a lot. There isn't this ticking time bomb in my pocket anymore, causing me to attack life voraciously. I'm not in as much of a hurry, and I credit that, primarily, to time. I was lucky enough to have been given quite a bit more of it than originally thought, and I've used it to forge lasting friendships, memorable love stories, great experiences and, currently, contentment. Although my physical health is nowhere near where it was a couple of decades ago, and this disease now packs quite a daily punch, I have finally found some inner peace.

I do believe that working with a qualified therapist as early as possible can help the mind grow in more positive ways than trying to go it alone. The story I told myself years ago became the story I lived by, and all my fears and worries drove the story. I may have had a less tumultuous emotional journey if someone had interjected alternative thoughts at an age when I was more impressionable. Though I wish it had been sooner, I'm glad that I took the time to figure myself out. It wasn't easy, and it isn't for everybody, but it definitely helped me to become less fearful of my future, and to tame the dragon within.

At 51, I'm very grateful for my quieter existence and all the inner strength that I have accumulated over the years. I no longer have the energy to live a life of constant movement. But the energy I do have never ceases to surprise me. When I was 21 years old fearing how I could possibly live with declining lung volumes, I would not have imagined that 30 years later I could still function quite well with FEV_1s that threaten to fall below 40 and sometimes do. It's not as easy as it once was, nor as crippling as originally feared. I find inspiration and gratitude in the simple pleasures and in my ability to always bounce back when my body undergoes yet another downturn. I also look for inspiration in those who share this disease and are coping with their own daily challenges from it. Our numbers are growing, and the life experiences gained, collectively, from all of us are more telling than any story I may have believed about a short-lived life, with no real legacy to leave. It just may be our real stories that will help the next generation diagnosed with this disease to be the healthiest one yet—from head to toe.

Debra is 51 and has CF. She is a part-time accountant who lives in Roselle, Illinois, with her husband, Adrian. You may contact her at: debraradler@hotmail.com.

Information From The Internet...

Compiled by Laura Tillman

PRESS RELEASES

Bacterium Infecting Cystic Fibrosis Patients Genetically Evolves to Live in Lungs and Evade Antibiotic Treatments

The bacterium that's the most important pathogen in patients with cystic fibrosis (CF) has genetically evolved and adapted to survive in CF-infected lungs and evade antibiotic treatments. Pseudomonas aeruginosa (Pa) is called an "opportunistic pathogen." The scientists performed the first systematic analysis of entire genomes (the full genetic "blueprint") for multiple "epidemic and non-epidemic" strains of Pa. Their analysis showed that the main drivers for the evolution and adaptation of the bacterium are the CF-lung environment itself and the presence of antibiotics. Better understanding of how the pathogen evolves will help advance more effective treatments for infected CF patients.

Scottish Drug Maker to Make Cystic Fibrosis Inhaler

NovaBiotics signed the agreement with Bradford-based Crystec to develop a dry powder form of its Lynovex drug. Lynovex is an "orphan drug" candidate that breaks down mucus, disrupts bacterial films and acts as an antibacterial agent. Lynovex could offer the possibility of a multi-functional, single treatment that addresses mucus production, bacterial infections and also persistent bacterial biofilms. NovaBiotics is also preparing to begin a phase-two clinical trial for Lynovex tablets that could be used to treat acute exacerbations of CF.
http://tinyurl.com/lnjyv67

California Company Creates Medical

Continued on page 25

Breath and Body

By Jess Newport

Keeping it all together for a healthy person is tough in this day and age. Not lying in bed and having a breakdown is beyond difficult for a person with cystic fibrosis. Ask me!

I pride myself in the fact that I had never taken an antidepressant until college. When my health was getting precarious and I was taking a full course-load, I began speaking with a psychologist. It became mostly a struggle to find little moments of happiness amongst studying and therapy. Since then, I have seen a therapist who makes weekly in-home visits and a psychiatrist who is used to patients who smoke crack. I've also experienced lots of Paxil, Zoloft, Lexapro, Remeron, Klonopin and Xanax (not all at the same time!).

But six years of medical help hasn't been as beneficial as my yoga practice has. When I moved to Durham in August of 2012, I was looking for new things to do in the area. My yoga instructor, Eleanor, had a weekly Monday night class that I began taking. Her class promotes self-feedback and encourages everyone to set goals to try to achieve in the 75-minute class.

Every Monday night, I construct a mind-body connection and facilitate self-talk. I have learned to acknowledge my current feelings at the beginning of class, and then set them aside and concentrate on how my body feels as I match my body to Eleanor's. Many mental health professionals will tell you about both the benefits and disadvantages of distraction. After enduring a week full of strong feelings, it is a relief to turn them over in meditation and concentrate on each Asana (yoga position). Because each Asana requires physical and mental focus, I cannot dwell on that fight I had with my best friend last Thursday.

JESS NEWPORT

Besides the concentration, yoga requires breath work. When I breathe, I imagine inhaling positive energy and exhaling negative feelings. This is a large part of meditation. I wonder how different yoga would have been with my CF lungs. Because I had my lung transplant four years ago, I have only practiced yoga with "normal" lungs. Yoga is a great form of exercise for my lungs. My PFTs are the highest I've ever remembered, and I believe my posture has improved due to the strengthening of muscles around my chest and back. Many yoga moves involve an "opening" of the chest with the intent to "lift" the heart and just shine it out!

The end of class finishes with 10 minutes of Savasana, or rest. The hard work I've put in leaves me exhausted. I lie and reflect on how I feel. I bask in an afterglow of harmony and feel content. Because I feel so physically healthy these days, I am happier and more mentally well. And I do believe that because I'm happier, I'm healthier. It's a circle of health that can be either vicious or rewarding. Yoga rewards me every Monday and I try to find that happy place the rest of my week.

Jess is 27 and has CF. She lives and crafts in Durham, NC.

Survivor

Am I really?
Two new-to-me lungs
With nothing much to show
for it.

Am I really?
Still stuck with tubes and regret.
A backpack symbolizes more
than nutrition.
A chip on my shoulder.

Am I really?
More time at doctors' offices
than home.
What is home anymore?
A place where I can leave all
this behind.
Not likely.

Am I really?
Crawling towards independence
One step forward, two back.
I'm tired of walking.

I survived transplant, but can I
survive the aftermath?

– Jess Newport

cfri Cystic Fibrosis Research Inc.

27th National Cystic Fibrosis Family Education Conference

"The Changing Faces of Cystic Fibrosis: Inspiring Hope"

August 1 - August 3, 2014

Sofitel San Francisco Bay - Redwood City, CA

Our annual conference brings together experts in the field of CF to provide the latest updates in research and care to our diverse CF community.

Speakers Include:

Ahmet Uluer, MD DO - Boston Children's Hospital
Antoinette Moran, MD - University of Minnesota Amplatz Children's Hospital
Marty Kharrazi, Ph.D. - California Dept. of Public Health
Thomas G. Keens, MD - Children's Hospital Los Angeles
Katherine Van Loon, MD - UC San Francisco Medical Center
Stephen Jones, NP - Children's Hospital - Albany Medical Center
Isabel Stenzel Byrnes, MPH MSW - CF Advocate, SF Bay Area
Mary Elizabeth Peters - Theatre Artist & CF Educator, Boston

Early Bird Registration (on or before 7/1/14)
$180 per person
Regular Registration (after 7/1/14)
$215 per person

Registration includes meals, reference materials, and access to all presentations and support groups.

For more information, visit
www.cfri.org • or call 1.855.cfri.now

To ensure good health for all, please use proper hygiene practices. All participants/guests with CF must comply with CFRI's Infection Control Guidelines.
See www.cfri.org for specifics.

CFRI Teen and Adult Retreat

"Relax, Recharge, Rejoice at the CF Zen Retreat"

July 27 - August 1, 2014 • Vallombrosa Center

For more information, visit• www.cfri.org or call 1.855.cfri.now

Just Deal With It

By Laura Tillman

My husband, Lew, and I have the same philosophy about life: "whatever comes your way, just deal with it." Easier said than done at times, but we persevere! This philosophy has been duly taxed a few times throughout our almost 39 years of marriage. The first time we genuinely struggled with it was after a major auto accident (the other driver's fault). The deaths of family members and our fur-kids have also tested our philosophy. And then there was the diagnosis of CF that came along a few months before our 20th anniversary. Lew took it in stride – for my sake. The reality of just how this diagnosis was going to change our lives hit me hardest after our training session with the PT; Lew had the pleasure of learning how to beat on me legitimately – not that he ever beat on me illegitimately! As we left the hospital I wailed, "What are we going to do?" and his reply? "We'll deal with it." Short, succinct and to the point! And so we did. I actually thought I was doing fairly well in my dealings with all that CF had brought into my life. I was hospitalized about a month later and then sent home on IV antibiotics. I missed two weeks of work, and during one of those long, long 14 days, I looked out the window, screamed, "Why me?", stamped my foot, stomped around the room and that was that. I've since dealt with whatever CF throws at me, as does my husband and the fur-kids.

Lew and I each have a weird sense of humor that helps us to "just deal with it." I remember during one of the earlier days of doing CPT, Lew started beating in a rhythm and dancing in place. It cracked me up! And, of course, his comment was that we have to make it fun or we'll go crazy.

My sense of humor is a bit more cerebral, rather than physical. I had an ongoing joke with my CF doctor about aliens for many years. My symptoms and cultures were sometimes quite interesting – as in the time my doctor sent me a culture report with the words: "Your cultures never cease to amaze me. I haven't heard of this one so had to look it up." Oh, great. So, I told him that I'd been abducted by aliens and they were running tests on me. They were actually trying to see what it took to break me, so it was a psychological test done through physical manifestations of CF. Whenever I had strange symptoms, I'd complain that the aliens were once again "testing" me. I referred to Pseudomonas as Sue D. Monas. I brought paint chips in to clinic to show my doctor the exact color of my sputum when he asked about that particular aspect. During a protracted hospitalization, the attending physician came in to my room to tell me that I might be going home in a few days. My response? "Oh, no! I can't! I just sent my change of address into the post office." This doctor had absolutely no sense of humor and just looked at me as if I'd gone insane! Humph. He never laughed at any of my "sick" humor. What a sourpuss.

> "Then there's chocolate. Ah, my elixir of life. A good dose of chocolate can soothe many of life's complications."

This is not to say that I don't have my moments. Some things are just so frustrating and exasperating and when I'm not feeling well, I have no tolerance. So, yes, I yell, scream and even swear – especially at the medical insurance representatives who know nothing and proceed to tell me what I can or cannot have for treatments/medications. How dare they tell me that my enzymes, which were covered the previous month, are no longer covered? And when I get mad, I take action although, sometimes, it's not positive action. It really doesn't help my case to swear and scream at the person on the other end of the phone, but it sure releases a lot of my anger!! If I can't talk to the person I wish to speak to, I'll send an e-mail, scathing or mild, depending on my mood. Usually, if I'm not dealing with an exacerbation when something happens, I can remain calm and restrained and deal with it quite rationally.

Then there's chocolate. Ah, my elixir of life. A good dose of chocolate can soothe many of life's complications. Being able to sit and munch on some fine chocolate can help calm the nastiest beast within!

And exercise…going to my Pilates class or walking with neighbors can have a tranquilizing effect. Pilates requires my concentration and I'm able to forget all of the frustrations for that one hour of activity. Walking with my neighbors is an opportune time to discuss issues and get others' opinions. Conversely, it's a time to hear about other people's problems and realize that mine may not actually be so bad.

Continued on page 25

PHOTO BY MARGARET MYERS

Rhythm

Rhythm, the essence of life,
helping to soothe my soul.
Music is a medicine.
It keeps CF from taking control.

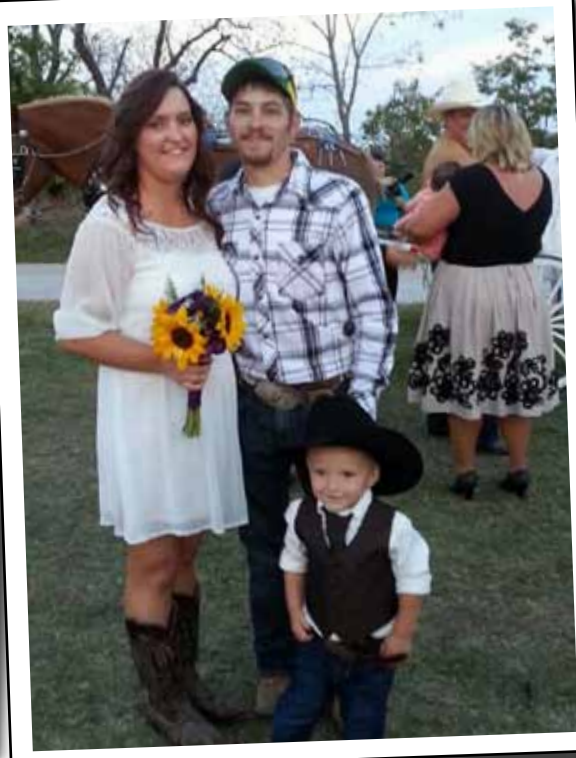
When all is calm
and the fire burns bright,
you will find me with my drums
standing in the light.

-A. Jenkins, 2000

"Through the Looking Glass: Images of Adults with Cystic Fibrosis" and "Caregiver Stories" are projects of Breathing Room, a non-profit organization. Breathing Room hosts these and other projects to facilitate open and candid communication in the CF community, supports the development of a community of adults with CF and provides education and insight for families, caregivers, and medical professionals who impact our lives.
To learn more about us and view more images in the collection, please visit our Website at:
http://www.thebreathingroom.org

FROM OUR FAMILY PHOTO ALBUM...

LAURA TILLMAN AND HER DOG, KIRBY.



AMBER AND BLAKE DURHAM WITH THEIR SON, TANNER.

JESS NEWPORT

ADAM AND SUSIE BALDWIN ON VACATION IN ZUNI, NEW MEXICO.

A ROMANTIC LUNCH FOR TWO: DEBBIE RADLER AND ADRIAN GULINSKI, OCEAN SPRINGS, MS.

PAUL FELD AND HIS GRANDSON CHRISTOPHER WHORTON.

Death of a Former Director of USACFA
Kurt James Robinson

July 7, 1983 – March 6, 2014

Kurt Robinson was a very happy man. He loved life and loved his family. He brought a real zest for living to his four years as a Director of USACFA. He served on the board from mid-2005 to mid-2009. In *CF Roundtable*, he wrote about his life and his love of coaching. He shared that love of coaching with the love of his life, his wife, Lisa.

Kurt was born July 7, 1983, in Portland, Oregon. He lived most of his young life on the Oregon coast in Newport. He lived the last several years in the Willamette Valley at Corvallis, Oregon. After graduating from Western Oregon University, he worked for Platt Electric in a job he loved.

Kurt had bilateral lung transplants in December 2012. After his surgery, Kurt started to speak to groups on behalf of Donate Life Oregon. He had hopes of going to the Transplant Games of America in Houston, Texas, in July 2014 to participate as a lung-transplant recipient.

He did very well for a while after his surgery but, eventually, he started having problems. He was awaiting re-transplant at the time of his death on March 6, 2014.

Kurt is survived by his wife, Lisa, and their son, whose birth is expected in June. We know that Kurt will be missed by all who knew him.

CREATIVE DISENGAGEMENT

The Allure Of Details [And, Maintaining Mental Health]

By Jim Chlebda

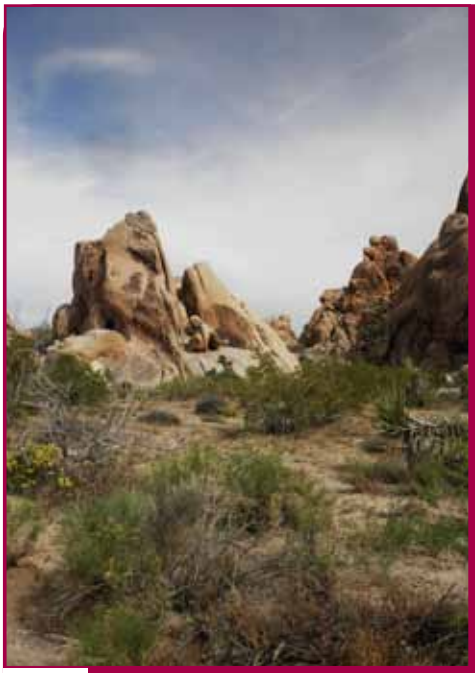
Whenever I am outdoors, I am struck by the sheer immensity of nature's scale. It is of particular note out here, hiking in one of California's expansive desert regions. The vastness and wide-open starkness a desert presents at first glance – I start feeling pretty small pretty quickly when I head out for a stroll – there is *a lot* of sand out yonder! However, if I scale down from this sea of sand and rock, my camera's viewfinder is the ideal co-conspirator in narrowing my search for compelling snapshots when focusing on possible points of interest.

[This month's *Focus* topic is a natural fit. As I explained earlier *(CFR, Summer 2013)*, I've always relied upon *Creative Disengagement* to purposefully shift my creative and mental gears into *"refresh"* mode. Fast forward three more decades and we've the technology to take fairly good pictures with fairly inexpensive cameras – without the need for any film to purchase and develop – now that's an artist's dream come true! These days, when I head out the door for *"refreshment,"* my little Olympus will usually be stashed in one of my pockets. If anything irresistible pops up, I can dive in and, later, see what sticks.

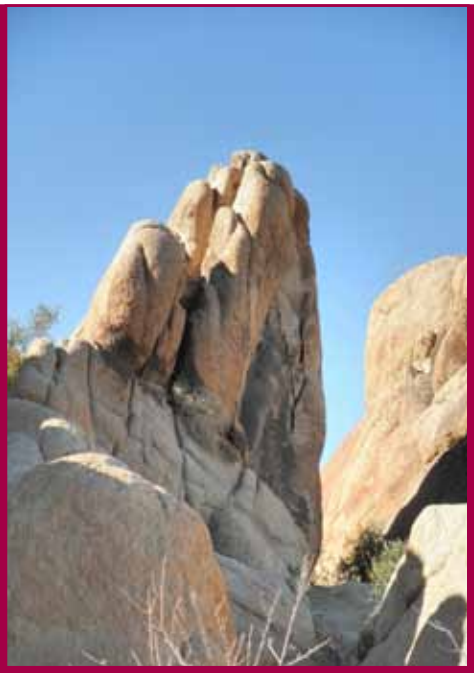
Mental Health Plan B: conversation and plenty of laughter with good friends; a good book; my guitar; pencil and sketchpad; paint and canvas – each great substitutes when the weather takes a nasty turn.] ▲

Jim, 56, has CF. He resides on the edge of Joshua Tree National Park in California. You may contact him at: james@back40publishing.com.

AN OAK TREE, YUCCAS AND DORMANT SHRUBS AT THE BASE OF A ROCK FACE ADJACENT TO RYAN MOUNTAIN.



ALONG THE TRAIL TO INDIAN COVE.



A SANDSTONE FORMATION RESEMBLES A PAIR OF PRAYING HANDS IN INDIAN COVE.

DESERT DAISIES WITH SLABS OF ROCK ALONG THE TRAIL DOWN TO 49 PALMS OASIS.

TILLMAN *continued from page 20*

And that's another important way that I "just deal with it." There always is someone out there who is a lot worse off than I am. I need to focus on the positives in my life and be thankful for all that I do have.

So, what else could there possibly be to help me cope? I don't need to take medications or see a counselor because I have – TAH-DAH – my fur-kid!!! When I was first diagnosed, my fur-kid at the time, Cooper, was always there for me. If I was home doing IVs, he never left my side. If the home care nurse came over, he wouldn't budge from the room, entangling himself under a table so that there was no way to physically remove him (home nurses have this "thing" about not wanting fur-kids in the room when dressings are being changed). Cooper always made his point and the nurses learned to just deal with it!!! Cooper hung out wherever I did my treatments; he went on walks with me when I took early retirement and felt at a loss. Cooper was my daily rock. And now there's Kirby. Oh, my. Kirby has a zest, a zeal, an enthusiasm for life that just delights me to no end. How can I possibly stay mopey or weepy when Kirby is there, whining and making his noises that indicate he wants my attention? And when I'm just sitting there petting him, a calmness overtakes the two of us. And then there are Kirby's antics, which make me laugh and think that life isn't so bad. Look how much pleasure Kirby takes in the simplest things in life! When he violently wags his tail, smiles and gives me kisses (I know, how can a germ-a-phobe let a fur-kid kiss her?), it just tickles me to see him so happy. To be the recipient of that unconditional love and to know that I made a difference in his life is extremely fulfilling.

So, there you have it. There's nothing really magical or unique in my efforts to maintain my sanity and outlook on life. I just deal with it one day at a time.

> "Pilates requires my concentration and I'm able to forget all of the frustrations for that one hour of activity."

Laura Tillman is 66 years old, lives in MI, is still happily married to Lew, and dotes on her fur-kid, Kirby. She is a Director of USACFA and is the President. Her contact information is on page 2.

INFORMATION *continued from page 17*

Device That Could Change the Course of Medicine as We Know It. Vaporizer Technology Used in E-cigarettes Could Allow New, Easy Delivery Method for Pharmaceuticals, and Offer New Hope for Asthmatics, Migraines, Cystic Fibrosis, Diabetics and Many More.

Alsa Refinish, LLC, has process and utility patent applications in place for a revolutionary medication delivery method. If successful, Alsa will hold patents for a device that delivers medications and herbal preparations directly into the lungs through vaporization, or "vaping." It incorporates technology used in vaporizing pens and e-cigarettes, and, in addition, adds Alsa's proprietary stationary mouth tube design. Alsa's innovative vaporization technology advances have created devices that can precisely measure and deliver medication. Vaping the drug would deliver it directly to the smallest areas of the lungs via harmless vapor. Patients who have CF could replace their inhalers with vaping devices to disinfect and treat the mucus with mucolytics in their lungs. In addition to delivering medication through the mouth, vaporization can be used to administer medication nasally. This method of delivering medication doesn't pass through the stomach and liver, so it prevents loss of potency. In this way, vaping devices have the potential to treat diseases more easily and quickly.

http://tinyurl.com/kjc2uqv

AIT Initiates Phase II Clinical Trial of NOxCureCF for Patients With Cystic Fibrosis

Advanced Inhalation Therapies has begun enrollment in Israel for a multicenter, open label, Phase II clinical trial of NOxCureCF, a respiratory treatment for patients with CF. NOxCureCF is a specialized formulation of inhaled Nitric Oxide (NO) delivered using AIT's patented drug delivery system.

http://www.news-medical.net/news/20140108/AIT-initiates-Phase-II-clinical-trial-of-NOxCureCF-for-patients-with-cystic-fibrosis.aspx

Bacterial Food Web May Be Key to Cystic Fibrosis

Researchers have shown that *P. Aeruginosa (Pa)* virulence is "turned on" when it feeds on a particular fermentation product called 2,3 butanediol, demonstrating a direct metabolic

Continued on page 26

My New Frienemy – Mental Health

By Paul Feld

I never thought writing about mental health was a topic on which I could elaborate. My, how things have changed in the last year! While I never could be portrayed as a joyful or exuberant person, I usually carried myself with a smile and did what I could to help others. These days my friends and family are helping me get by, day-to-day, with the challenges I face. Every day it seems like a new health problem brings itself to light or an old one pops up again to remind me how fragile I am. The things I really enjoyed doing just a couple years ago seem so difficult now, I wonder at times if it is even worth pursuing them any longer.

I am currently approaching my 57th birthday. I have always recognized every birthday as a goal achieved. This year, for the first time, I started to ask myself if it all is worth it. Back in the day, I used to write off bad days as something that will wither away soon and I'd be back on track in no time.

> "I am currently approaching my 57th birthday. I have always recognized every birthday as a goal achieved."

These days, I seem to deal with a problem that I know will return sooner or later and add this to the long list of crap I already deal with, frequently.

Five years ago, I had a single pulmonary specialist who would guide me through the healthcare maze as needed. I would go to another specialist, for a short time, to deal with a particular issue and then, feeling comforted, I probably would not see him/her again. Now, I regularly see a pulmonologist, a urologist, a nephrologist, a dermatologist and a gastroenterologist. In addition, I see my dentist and an endodontist regularly. Most of these folks ask to see me every three months, if not more often. This is just the doctors and does not include my monthly IVIG (Gammagard) infusion, pentamidine treatment and lab draws for my potential upcoming kidney transplant.

I am immuno-suppressed, diabetic, in stage-4 kidney failure, and have frequent gout attacks. I can't sleep, I

INFORMATION *continued from page 25*

relationship between fermenting bacteria and Pa. This understanding could lead to more effective treatments for CF patients; rather than the use of antibiotics, disrupting *Pa's* flow of preferred food could be key to preventing CF-related infections in the lungs.
http://www.news.cornell.edu/stories/2014/01/bacterial-food-web-may-be-key-cystic-fibrosis

Women With Cystic Fibrosis Exhibit Higher Insulin Secretion Than Men

In patients with CF, adult women demonstrate higher insulin secretion than their male counterparts, suggesting a potential sex dimorphism in this disease. Women with CF had insulin secretion levels comparable to those of healthy women, whereas men with CF had significantly lower insulin levels than healthy men. The researchers said these findings ran counter to their hypothesis, and their full implications are not yet clear.
http://tinyurl.com/lm9ba9a

Scientists Grow Human Lungs in Lab

U.S. researchers who were the first to successfully grow human lungs in the lab say their break-through could eventually save the lives of people waiting for a lung transplant. The scientists grew their first human lungs in the lab last year and said they hope to transplant the first set of lab-grown lungs into animals this year or next. But it could be five to 10 years, or even longer, before it might be possible to use lab-grown lungs to save the lives of people who need new lungs.
http://tinyurl.com/nvo9oja

Garlic Counteracts Virulent Bacteria

There is a potent chemical compound in the garlic plant that neutralizes resistant bacteria by paralyz-ing their communication system. Ajoene – the substance present in garlic – specifically prevents the bacteria from secreting the toxin rhamnolipid, which destroys white blood cells in the body. White blood cells are indispensable because they play a crucial role in the

am always cold, and this winter is driving me (and half the country) into depression. On the positive side, my lungs, given to me by David S. almost ten years ago, are performing very well and pulmonary issues seem to be the least of my problems.

On the day of and after my IVIG infusions, I come home, go to bed and shiver for about 18 hours. Then, things calm down. That's two days of every month shot to hell. Include two to three more days monthly of some sort of doctor visit (and/or follow up), gout attacks etc., and about a week of every month simply sucks dealing with health issues.

On one hand, I am blessed. I have insurance through my wife and my costs are minimal. On the other hand, I add up in my head that this country, somewhere, spends more than $150,000 keeping me alive every year – mostly on drug costs and infusions. Being retired five years now, I honestly ask myself if I'm worth it.

I don't "work" anymore, although I do volunteer for USACFA and my church. I may put in 40 hours a month on a hard month. Is 400 hours a year of volunteer work worth $150K or more annually? Should I even be looking at things in that light? I know I provide encouragement to family and friends, as many have told me so, and I am certainly blessed to have them around. Sometimes, however, a day can be very hard and I ask myself, Should I just move on to whatever is next? I seem to be asking myself that a lot lately. Thank God I have faith that there is something next and have little fear. I don't think I need to talk to anyone about it. In fact, just writing this article provides a vent for me, but certainly mental health is no longer an abstract obsession other people have. It's now hitting me right between the eyes.

Paul is 56 and has CF. He is a Director of USACFA. His contact information is on page 2.

immune defense system, not only warding off infection, but also killing bacteria. When bacteria clump together in what is known as biofilm – where they surround themselves with a tough film of organic materials – they become resistant to antibiotics. Ajoene supports and improves treatment with conventional antibiotics. When anti-biotics are added to biofilm they have very little effect, and ajoene alone barely makes any difference. Combination treatment with ajoene and antibiotics kills more than 90 percent of the normally virulent biofilm. From a technical perspective, the ajoene blocks the communication system – known as Quorum Sensing – in the bacteria.

http://tinyurl.com/kj4gmbx

CURx Pharma Joins Gilead to Develop FTI for a CF-Related Lung Infection

CURx Pharmaceuticals will team up with Gilead Sciences in developing its broad spectrum combina-tion antibiotic Fosfomycin:Tobramycin for Inhalation (FTI) to treat a form of lung infection in CF pa-tients. FTI (formerly known as GS 9310/11) is a combination of the antibiotics fosfomycin, an antibiotic with activity against gram-positive and gram-negative bacteria, and tobramycin, an aminoglycoside antibiotic with potent gram-negative activity. FTI is designed for treatment of

Continued on page 33

CLUB CF ONLINE

The focus of Club CF is: LIVING BREATHING SUCCEEDING. Club CF wants those who have CF or are affected by the disease to see that, despite all the challenges that come along with cystic fibrosis, it is possible to live a happy and successful life.

Club CF shows how people in different age groups (20+, 30+, 40+, 50+, 60+, caregivers) are succeeding. Through Club CF, people can give hope and inspiration to those who are hesitant or nervous about what lies ahead of them.

People with CF are succeeding and making a difference in the world in high school, college, sports, careers, relationships, starting a family, post transplant, and disability. If you are one of the many people who are LIVING BREATHING SUCCEEDING, join Club CF and show the world what you have done! To learn more, please visit us online at: www.clubcysticfibrosis.com

Club CF is sponsored by The Boomer Esiason Foundation, which is committed to showing the world that people with CF are living longer & fuller lives, and by generous support from Genentech.

Worrier Princess

By Andrea Eisenman

I am definitely a worrier. A princess? Far from it. In the past, if left unchecked, I could obsess and worry about too many things. I worry about my health, my mom's, my dog's, will I get this done in time (taxes!), will I forget this or that? I have realized over the years that by worrying, one gets nowhere except ill. Worrying can lead to anxiety and stress. And we all know stress is very bad for people with pulmonary issues. It can make us breathe in a shallow way or bring on hypertension, it can cause a decrease or increase in our eating, we can get more frequent stomachaches, headaches etc. It becomes hard to function optimally.

As people with cystic fibrosis (CF), we have a lot to keep track of and worry about; from treatments, medications and wellness level to more dire things, like dying from CF or being incapacitated from loss of lung function. On and on it goes. Then throw in caring for a loved one – parent, child, spouse etc. How does anyone stay on top of it all? And, how does someone stop worrying about everything? There's no simple fix or answer.

These are some things I have done to reduce my stress and anxiety when I am going through something that worries me. While there are different levels of worry, I try to not get mired down in it all.

At first, I sometimes become overwhelmed by worry or anxiety and am not able to do anything. Some of these things listed below help me out of this immobile state. Usually it is taking an action that makes me feel like I have accomplished something. I will normally bike or get active. When I am biking at home, I have the television going to distract me, which makes me stop worrying about what is troubling me for about 30-40 minutes. Then after that, the endorphins might kick in and I am not so upset anymore. Or, I feel like one of my to-do items was accomplished. Another thing I do is play tennis. While this is not something I can do spur-of-the-moment, since I play

ANDREA EISENMAN

doubles, it is great for not thinking about anything too complicated. When playing doubles, I have to really focus on what I am doing right then and there. Somewhat being "present." Otherwise, my partner will get annoyed with me for missing too many shots or I will get beaned in the eye socket – it has happened.

During the warmer months, I can play more tennis and get a lot of joy out of it for the reason that it does take me out of myself and my concerns, if only for that time I am playing. Plus, it helps clear any secretions from my lungs and sinuses.

Alternatively, sometimes taking a nap is all I can handle. If I can fall asleep, which is usually not a problem during the day, I will do that to "reset" my wiring. Sometimes, I wake up feeling refreshed and able to tackle the problem head-on. Other times, I need to try another method of reducing anxiety.

When exercise or sleep are not feasible, I try to figure out what is really bothering me. If I am upset or angry, I let myself feel it and, if possible, talk to someone I feel comfortable sharing it with. It sometimes feels good to discuss it and get someone else's opinion and perspective. I do not want someone to say, "Oh, don't worry, it is nothing." That doesn't validate my feelings that I am having. But rather, I need someone to let me vent about something and empathize. For this reason, and to not drive my friends crazy, I see a therapist. He is very helpful in empathizing with me and trying to get me to see the other side of things as well, not just my own myopic view of a situation.

Seeing a therapist and working on long-term issues that arise helps a great deal because, unlike with close friends or my family, a therapist may have an unbiased perspective. They do not have an ax to grind or feel the need to make you do anything. Through therapists, I have been on antidepressants. And while I think I cycled through almost every one at some point in my life, I currently am trying to not take another medication if I can avoid it. I have found that some of these medications come with so many side-effects that I usually stop taking them for those reasons, even though they helped me get through a difficult

time (while waiting for lung transplant is an example).

There have been times that I have gotten dehydrated and, when that happens, severe anxiety overcomes me. So, I have added Ativan to my medical arsenal. I rarely take it for anxiety, but it does help me sleep during times of stress or when my hormones are up and down. I took this drug a lot recently when my mom was in the hospital for pneumonia. I was very worried and was not sleeping well. But to be of any use to her or myself, I knew I had to get some sleep and therefore relied on Ativan to help. Because it can be habit-forming, I try to take it only when absolutely necessary.

One of the greatest things I did was I learned to practice Reiki, a Japanese healing and balancing technique. This has been a great addition to my coping skills. Anyone can learn it. I took my first class in 2011 for my first-degree learning and then completed the second-degree class two years ago. Since then, I practice on myself every day and sometimes others who enjoy the treatment. I never meditated, but it is similar or probably what meditation feels like. It is quite relaxing and sometimes I fall asleep doing it. But usually, I complete the hand positions involved and feel refreshed. Like a meditation, it can take about 20-40 minutes. It not only clears my head but makes me feel mindful of things that I cannot think of when I am stressing and worrying.

> "I have realized over the years that by worrying, one gets nowhere except ill."

Other benefits to practicing Reiki have been fewer stomachaches, better digestion, fewer sinus infections, and fewer colds. I even started getting my period more regularly and felt less inflammation in my body. But more than anything, I love being able to do this for myself. It makes me feel proactive and that is empowering.

Usually, we stress over things that bother us that cannot be changed, which leads to loss of hope. That can cause depression because we feel that whatever we do, we will not change the outcome we are dreading. But we, as people with CF, are problem-solvers. We have had to be for all we go through on a daily basis. Maybe we have to think about other things first, divert our attention to something that will distract us and eventually come back to our problems. I guess the items above help me cope and then get me to refocus on what the problems are so I can try to solve them in my own time.

Andrea is 49 and has CF. She is a Director of USACFA and is the Executive Editor of CF Roundtable *and is the Webmaster. Her contact information is on page 2.*

Information For People Who Travel On Airlines

In December of 2011, the Transportation Safety Administration (TSA) introduced a toll-free helpline that answers questions for fliers with disabilities and medical conditions. Disabled travelers may call ahead about screening policies, procedures, and what to expect at the security checkpoint. The purpose of the new helpline is to inform passengers with disabilities about certain policies before they fly so they may properly prepare for travel. The helpline may be helpful for people with cystic fibrosis who must travel with durable medical equipment, portable breathing machines, needles, liquid solutions (inhalant medications, insulin, etc.) and other medical equipment.

Travelers are encouraged to call at least 72 hours prior to a flight. People with CF and other medical conditions may call the "TSA Cares" toll-free number at: 1-855-787-2227. The helpline is available Monday through Friday, 9am-9pm (Eastern Time) and is closed on all Federal holidays.

Individuals also may find information on traveling with special medical needs on the TSA Website at: http://www.tsa.gov/travelers/airtravel/disabilityandmedicalneeds/tsa_cares.shtm.

WELLNESS

The Other Chronic Illness

By Julie Desch, MD

I don't write much about mental health, probably because I like to be a bit flippant in my writing, and I can't do that when discussing psychiatric illness, something that has played a prominent role in my life. My mother was extremely ill with both severe depression and a generalized anxiety disorder throughout the vast majority of our time together on this planet. Certainly, she had a genetic predisposition to her condition, but I have no doubt that the never-ending stress of raising three children with cystic fibrosis is what put her over the edge. Burying two of them kept her there.

The sad truth is that she was misdiagnosed for years, and every treatment known in psychiatric medicine at the time was attempted to try to relieve her recalcitrant depression and panic attacks. She received antipsychotics even though she was not psychotic, she was inundated with antidepressants and neuroleptics of yesteryear, none of which worked. She even had electroshock therapy several times. I still can't watch *One Flew Over the Cuckoo's Nest*. There were long absences when she would be hospitalized, and I would be looked after by my older siblings while my father tried to hold the family together. Mental illness consumed all of the energy that CF didn't steal in our family. No wonder my sister became a psychiatrist.

Eventually, when I was an adult, SSRI (selective serotonin reuptake inhibitor) medication was found to help her more than anything ever had in the past, and she had some better years. But the decades of psychoactive medications had taken a huge toll, and as a result, her entire life was dictated by messed-up synapses in her brain, just like our entire lives are affected by messed up chloride channels in our epithelia. Chronic illness sucks, and mental illness is no less disastrous than a physiologic problem involving the lungs or any other organ. The sad truth is that mental illness has a higher than normal prevalence in populations of people with chronic illnesses, and CF is no exception. Depression and anxiety are very commonly found in those with CF, and this is a problem that I don't think gets enough attention.

I don't even like to use the term "mental illness," because it implies that the problem all lies in one's psyche. Mental illness is based on genetics and the way molecules work or don't work in the brain, just as cystic fibrosis or muscular dystrophy result from genetic mutations leading to molecules that don't function optimally in the body. This genetic predisposition, combined with the cumulative stressors that accompany an ultimately fatal illness, is for many a knockout punch.

> *"Depression and anxiety are very commonly found in those with CF, and this is a problem that I don't think gets enough attention."*

JULIE DESCH, MD

I inherited my mother's predisposition to depression. In fact, I have had two major depressive episodes in my life, one as a child, when I ended up being hospitalized, and one as an adult, when I was completely unable to function normally for a long period of time. I also inherited her anxiety disorder and have experienced panic attacks, fortunately only on rare occasions. In my early thirties, I gave in and started taking an SSRI myself, and just as was the case for my mother, these medications have helped me quite a bit. Since starting them, I've been fairly free of depression and panic attacks. The random timing of my existence on earth during a time when these highly effective medications are available is the only thing that has prevented me from living the life of my mother, full of despair and fear.

Well, that might not be the only thing. I have also been fortunate enough

to afford years of talk therapy and to learn and practice the very helpful (and scientifically validated) practice of mindfulness meditation. In addition, now we know that regular exercise *on its own* can be as helpful as SSRI medication for some types of depression, and you all know the important role exercise has played in my life. It is only in retrospect that I know now how beneficial all of that exercise has been for my mental health.

There is a stigma around mental illness that I find frustrating. Even though many forms are clearly genetic and due to imbalances of neurotransmitters in the brain, countless people are embarrassed to need medication that helps rebalance the chemicals in the brain. An SSRI, for example, increases the amount of serotonin available within the synapses, or tiny gaps, between nerve cells in the brain. For some reason, some people lack sufficient amounts of serotonin in the brain, and this can lead to depression. Medications can correct this. Exercise and meditation help, too.

If you had your thyroid removed, and had to take thyroid hormone supplements for the rest of your life, would you be embarrassed? No, of course not. If you have diabetes, and need to take insulin to ensure that energy sources enter into your cells, are you ashamed? Absolutely not. Why should depression or anxiety, such common occurrences in the CF community, be viewed any differently?

The commercial is right: depression hurts. It feels like the weight of the world is preventing you from performing even the smallest of normal activities. Nothing is interesting and almost nothing feels worth it. Now add that feeling to the amount of effort necessary to keep our bodies functional…not a good combination. But depression can be very effectively treated, often with a combination of modalities. You just have to start by asking for help. When you are in the throes of a clinical depression, you really can't just "pick yourself up by your bootstraps."

Similarly, add an anxiety disorder to the knowledge that your disease is only going to get worse. Throw in a comment from a poorly informed doctor that "you should be dead." Maybe that doesn't happen anymore (I hope not). A panic attack feels like you are dying, right this instant, even though there is no obvious acute threat. Out of the blue, you feel like you can't breathe because your abdominal organs now reside on the floor, your heart is going to burst from your chest and all of the air has been sucked from the room. One psychiatrist told me that most of her patients were more paralyzed by the fear of having a panic attack than by the attack itself. From the few I've had, I can believe this. There are both medical and cognitive behavioral ways to improve such a disorder. You don't have to stay paralyzed.

I am glad that this issue is the Focus topic of *CF Roundtable*, because I think we need to talk more about it. I hope that this and the other articles here will help those who feel ashamed or embarrassed to seek help. Speak up in clinic. Trust me, your CF doctor knows that this can be a problem. There are definitely ways to make you feel better and, God knows, we need to be at our best to fight CF.

Julie is 53 and is a physician who has CF. You may contact her at: jdesch@usacfa.org.

COUGHING WITH A SMILE...

Buck Up Buttercup

By Jennifer Hale

Hello *CF Roundtable* readers! Hope this issue finds you all doing the best you can do. The topic today is "Maintaining Mental Health." What a doozy this topic is when dealing with CF or any terminal illness.

I would like to open up with a quote from Eleanor Roosevelt that I found to be so appropriate for this column's topic. "You gain strength, courage and confidence by every experience in which you really stop to look fear in the face. You are able to say to yourself, I have lived through this horror. I can take the next thing that comes along. You must do the thing you cannot do." I thought this was so appropriate in my walk, our walk, with CF.

CF is always about rolling with the punches and constantly rebuilding your physical self back up along with your mental self. I am constantly giving myself pep talks along with rebuilding my physicality at the gym every single day. CF has knocked me down so many times and one of my worst moments was recently fighting back from mycobacterium abscessus.

I am proud to say I have come back from the dark, but boy did it take a toll on my physical and mental health. What I like to do to keep myself in fighter mode is to talk it out with loved ones, talk it out with God, listen to music and read very inspiring quotes/songs/poems. I am sure those of you who have been following my column have come to realize I get a lot out of inspiring quotes. These quotes really speak to my soul, and I am able to refer to them, concentrate on them and memorize them to give me strength when I need it.

I keep a quote book, which is a spiral notebook of quotes, sayings and songs that I find really lift me up and that I can use to lift others up who have their own mental and health battles. A good quote really fires me up and makes me feel positive about what I am dealing with in terms of my health and my life. Here is one that I have put on a postcard from an unknown author, and this quote has really helped me:

I am bigger than this
I am not my struggles
I will survive this & overcome it
I will keep moving forward
Nothing will keep me down
I am a survivor
I will rebuild myself stronger than before
Watch Me

I am sure many of you out there can relate to that! We are constantly rebuilding our minds and our bodies as we fight and come back from our various exacerbations! And praise GOD and our hard effort that we do come back!!!

> *"Talking to loved ones really helps me not keep all this fear and sadness inside."*

JENNIFER HALE

Music is just food for the soul. There is nothing like a good song to lift your spirits and give you strength. When I was going through seven months of IVs recently, I found a lot of comfort in listening to music during my evening dose as I lay in bed. I was just so very sick, and lying there with the comfort of my music on my Pandora really got me through those evenings. I find it amazing how music speaks to my soul. It can make me cry, it can make me laugh, and it can make me want to get up and fight, fight, fight!

One of my favorite songs that really fires me up is from Sugarland and is called "Stand Back Up." When I hear it I think of myself singing it to my CF. It starts off by saying "go ahead and take your best shot/Let it rip give it all you got/ I'm laid out on the floor but I have been here before/ I may stumble, yeah I might fall." The chorus is "but I will stand back up/ you'll know just the moment when I had enough/ Sometimes I am afraid and I don't feel that tough/ But I'll stand back up!" Booo Yaaaah! I will stand

back up and I will get through whatever CF sends my way!

I also talk to God to maintain my mental health. I pray and I have an ongoing dialogue with the man upstairs, and I find the relationship helps me get through the tough times. It's not all pretty, my conversations. Sometimes I am yelling at Him and asking where the heck He is, and then sometimes I am humble and thankful for what I do have in my life.

Finally, talking to loved ones really helps me not keep all this fear and sadness inside. We all need to get it out and sometimes we all just need a hug. A quote from the Sookie Stackhouse books really sums up what it means to talk to, rely on and lean on people to get you through tough times. That character said, "Worries shared are worries halved." I feel it is important to let people in and to not be a hard stubborn shell. Nobody said the life of terminal illness is easy, and why should we have to do it all on our own? Gloria Vanderbilt once said, "We are not put on this earth to see through one another but to see one another through." I am blessed to have a husband whom I can truly lean on, and I am so thankful that I also have my parents and my mother-in-law along with my husband's side of the family who all see me through!

Well, these are some of the ways I maintain my mental health. It is not always easy and I am not always super upbeat about my situation. I do allow myself to feel dark and depressed if I need it, but I do not let it stay for long. I believe dealing with the hard things in life is easier and more pleasant believing there is a silver lining somewhere in the midst of it all. That is a quote from me! Until next time readers! Stay strong! ▲

Jennifer is 42 and has CF. She and her husband, Mark, live in St. Petersburg, FL. You may reach her at: jhale@usacfa.org.

INFORMATION *continued from page 27*

patients with CF, formulated as a liquid for inhalation with an aerosol device. FTI has demonstrated antibiotic activity against multiple pathogenic bacteria, including methicillin-resistant Staphylococcus aureus (MRSA), in preclinical studies.
http://tinyurl.com/p89bbl7

Insmed Provides Interim Update From Two-Year, Open-Label Extension Study of ARIKACE to Treat *Pseudomonas aeruginosa (Pa)* in Cystic Fibrosis Patients

ARIKACE is a form of the antibiotic amikacin, which is enclosed in nanocapsules of lipid called liposomes. This advanced pulmonary liposome technology prolongs the release of amikacin in the lungs while minimizing systemic exposure. The treatment uses biocompatible lipids endogenous to the lung that are formulated into small (0.3 micron), charge-neutral liposomes. ARIKACE is administered once-daily using an optimized, investigational eFlow(R) Nebulizer System manufactured by PARI Pharma GmbH, a novel, highly efficient and portable aerosol delivery system. The data showed that ARIKACE was well tolerated, and there was a sustained improvement from baseline level in Forced Expiratory Volume in One Second (FEV1). Patients also experienced a sustained reduction in density of *Pa* sputum while on treatment.
http://tinyurl.com/kg4ybtb

Vertex's Cystic Fibrosis Drug Approved for Another 150 U.S. Patients

Kalydeco, which was the first drug to treat the underlying cause of CF when it was approved in the U.S. in 2012, is now approved for patients with other gene mutations. The approval opens the door to similar aged patients with eight other mutations: G178R, S549N, S549R, G551S, G1244E, S1251N, S1255P and G1349D. In total, the number of U.S. patients with any of the eight mutations is estimated at just 150 patients.
http://www.bizjournals.com/

FYI

Cystic Fibrosis Database (CFDB): A new Web-based tool for cystic fibrosis specialists. Pediatric Pulmonology 02/19/2014.

The authors designed and developed a Web-based, free access tool called "CFDB"—Cystic Fibrosis DataBase (www.inetflow.it/CFDB). This tool, providing a quick overview of the available evidence in clinical research in CF, may help clinical decision making, designing of new trials and building guide-lines.
http://tinyurl.com/m44bpn3

The role of respiratory viruses in adult patients with cystic fibrosis receiving intravenous antibiotics for a pulmonary exacerbation. C. Etherington, R. Naseer, S.P. Conway, P. Whitaker, M. Denton, D.G. Peckham. Journal of Cystic Fibrosis. Volume 13, Issue 1, Pages 49-55, January 2014

Viral associated pulmonary exacerbations in adults with CF are associated with more severe pulmonary involvement and respond less well to standard

Continued on page 39

IN THE SPOTLIGHT
With Blake Durham

By Andrea Eisenman and Jeanie Hanley

After receiving an e-mail from a babybull_43, requesting to be interviewed for *In The Spotlight*, we were intrigued. A newbie to reading *CF Roundtable*, Blake took the initiative to be part of this column that he had just finished reading. He enjoyed seeing how others with CF cope with the disease. Like you and me, he sometimes struggles to find time to do his treatments. Luckily, his wife makes sure he does them. Lucky man! Blake comes to us from Summers, Arkansas, population 150-200. Not sure how many cows, though. He is a born and raised dairy farmer with some chicken-raising experience as well. Being a dairy farmer is hard work, and he gets all of his exercise from doing whatever it takes on the farm, from feeding and milking cows to repairing equipment to everything in between, keeping it running smoothly. He would not have it any other way. How many people do we know who enjoy their jobs so much? Probably his love of animals helps greatly. So much so, he and his wife are starting to breed Great Danes. He also has a passion for riding bulls and that was where we thought his e-mail moniker had come from, turns out we were wrong. Read on to hear how that came about. Please welcome our newest star. Spotlight, please!

Age: 24 years old

Marital status?

Married two years. I have known my wife since high school but we didn't officially meet until we were out with mutual friends one night and hit it off. She had just gotten out of a bad relationship and after talking a while I found out she was three months pregnant with his child! A month before the baby was due the biological father passed away from pneumonia so I stepped into the shoes of full-time dad and we now have a baby boy named Tanner Blake Durham. Four months after our son was born we got married. We have thought about adopting another child since, like most males with CF, I cannot have children.

BLAKE DURHAM AT WORK ON THE DAIRY FARM.

Is your wife involved in CF care?

Yes, she takes off of work as receptionist at the Fayetteville Auto Park so she can go to doctor visits with me. She also makes sure that between visits to the clinic, I do my treatments. And she does some research to keep us updated on what's available and what's coming out regarding new CF therapies.

Do you work?

I work on a dairy farm milking and feeding cows, baling hay and chopping silage. I feed calves and build fences, work on equipment and everything in between. If it's done on the farm I do it. I work on the farm an average of 10 hours a day, 6 days a week. Doesn't make my wife real happy, LOL.

How did you choose this kind of work?

I was born and raised on a dairy/poultry farm. Growing up, my job on the farm was to feed the baby calves to help out my mom and dad with chores! My grandparents and parents ran a 100-cow dairy farm along with three broiler-chicken houses. Farming is all I know!

How did you get your e-mail moniker, "babybull_43?"

It started while I was playing football when my coach called me "bull." He got it from the movie Bull Durham [Blake's last name is Durham] and the number 43 was my football number. Growing up with CF, I was obviously not the biggest person on the field, but my coach said I played harder and with more heart than anybody on the team so the nickname "bull" kind of went both ways. My mom started calling herself "momma bull" so my e-mail fell into place as "baby bull."

How were you diagnosed with CF?

I was diagnosed at four months through a sweat test! They started testing me for various diseases because I was not gaining any weight and had a dry cough.

How do you feel now?

I feel good but my lung functions are below where I'd like them to be.

Do you exercise?

I don't exercise in the aspect of jogging or a gym because my job is so physically demanding. What keeps me in shape is working on the farm.

What do you do for treatments?

I do a mix of albuterol and 7% hypertonic saline along with the vest twice a day. And then Pulmozyme at night. I also do one month on and one month off of inhaled tobramycin and ceftazadime.

Do you know your CF genetic mutations?

Double strand of the Delta F508.

Do you have hope that drugs like Vertex's Kalydeco will help you?

Yes, I can only wonder what it would be like not to struggle to breathe.

Have you ever participated in a clinical trial for CF?

No, because I live too far from my CF clinic, where I receive all my CF care and treatments. It's a four-hour drive one way.

Are you happy with your lung function?

No, because they are the lowest they've ever been.

What impact has CF had on your life?

The biggest negative impact that I've had to deal with is financial. With Medicaid and Medicare along with receiving Social Security, I can earn only so much money a month and it's not enough to provide for my family. If I earn more than the limit, I will lose all supplemental and medical assistance.

How often do you do IV antibiotics?

When I was diagnosed with CF, I spent the first year of my life in the hospital. I was in and out every two weeks. After the first year, I wasn't on IV antibiotics until I was 12 years old and that was for a two-week tune-up. Following that, the next tune-up was not until I graduated high school. Since then my CF has progressed and I do IV antibiotics once-a-year.

Any benefits of having CF?

When I attended college, I received the Boomer Esiason scholarship. That scholarship helped me out a huge deal in paying for school!

Funniest CF moment?

When my cousin and I were younger, he always wanted to give me my enzymes. So when he got to he would give me one and he would take one himself. He didn't know why he didn't get to take them and I did.

Whom do you admire the most?

I have always admired my dad because of how hard I've always seen him work on the farm no matter what it threw at him. I still admire him today because he was in a car accident 16 years ago and was paralyzed from the waist down and there is nothing that he cannot do. He does all of his own mechanic work and is totally self-sufficient. About the only thing he cannot do is change a light bulb. I admire that he has never given up despite what he has to deal with. I strive, every day, to not let my disease slow me down or make me different from anybody else.

Is there anything you wish you could do over again?

Looking back, I would have taken better care of myself after high school. I never realized how important my treatments were in high school because I was getting plenty of exercise and knocked around playing football so I never did them. Once I was not as active, my CF showed its face and now I struggle to keep it under control.

What goals are you currently working toward?

My wife and I are currently trying to start a small organic free-range chicken farm.

Where do you see yourself in five years?

I hope to see my son starting kindergarten and me operating the chicken farm.

Hobbies?

As a hobby, I ride bulls. As a young boy I loved watching bull riding at the rodeos and on TV. I always said when I got older I wanted to ride bulls, but my dad was completely against it. So I never really got to do it. After I graduated high school and moved out, I followed my so-called dream and started riding bulls at local practice pens and rodeos. Another hobby of mine is baling hay. I love driving the tractors and after a long day's work you can look out back and see what you've accomplished for the day, hundreds of round bales staggered across the field. Recently my wife and I have started breeding Great Danes. We love the gentle giants! In my free time, which is rare, I enjoy working on diesel trucks with some of my buddies. I'm also a big country music fan! On occasion, my wife and I go trail riding on our horses, when we both have time off at the same time.

Jeanie Hanley is 51 and is a physician who has CF. She is a Director of USACFA and is the Vice President. Her contact information is on page 2. Andrea Eisenman is 49 and has CF. She is a Director of USACFA and is the Executive Editor of CF Roundtable *and Webmaster. Her contact information is on page 2.*

If you would like to be interviewed for In The Spotlight, please contact either Andrea or Jeanie.

TRANSPLANT TALK

Farewell My Lumberlungs*

**"Lumberlungs" is a song by the band Slobberbone of Denton, TX*

By Susie Baldwin

Part 1

As I write this, I am approaching the 15-month-anniversary of my bilateral lung transplant. I feel better than I have in years and am full of gratitude, hope and excitement about the possibility of living to reach age 50 and beyond.

Like every adult with CF, my journey has been full of ups and downs, including the special time – the borrowed time, as I think of it – that I have lived beyond my transplant. There is nothing like nearly losing one's life to help a person be able to savor each day that she or he feels well enough to do so.

Before my surgery, I read a lot about the so-called "bumps in the road" that people experience post-transplant. Only in *CF Roundtable* did I find, with any specificity, other patients' descriptions of what these bumps consisted of. Perhaps it's because I am a physician, but I greatly appreciated knowing exactly not only what could go wrong but how people felt when things did. I hope others will benefit from reading some of my musings on the process, as told through social media postings and e-mail messages during the first six months of my life with new lungs.

"The Call"

On December 20, I spoke with the UCLA transplant coordinator before he left the country on his Christmas holiday and, based on my status and that of the other patients on the UCLA list, he specifically concluded that my transplant was not imminent. I figured I had a month to wait, maybe three weeks, maybe more, though it was getting hard to imagine lasting two months longer in the condition I was in.

The next day, to my utter shock, I got the call. I said to the transplant coordinator who phoned, at around

SUSIE BALDWIN

3:30 pm, "but I just spoke to Jay and I thought it wasn't going to happen yet!"

She said, "Well, you're coming up #1, do you want the lungs?"

"YES!!"

Facebook post

December 21, 2012

Today a 23-year-old man died suddenly of a brain hemorrhage and his family donated his lungs. I am scheduled to go to the OR within the hour, if all goes well, to receive them. Wishing his family peace and happy holidays to all of you. – at UCLA Med Center.

Facebook posts by my sister, Franny

December 22, 2012

Susie is out of surgery and in ICU...and she has a new set of lungs. – at UCLA Med Center.

December 23, 2012

Susie just took her first walk with her new lungs. A complete lap around the ICU floor.

December 24, 2012

Susie is breathing on her own for the first time in a year. The oxygen – that she has not been able to live without – has been removed.

Facebook post

January 2, 2013

What a way to start the New Year! I can't describe what it's like to have emerged on the other side of this surgery – past the fears of being wheeled away to the cold OR, past the fears of voluntarily surrendering the lungs that have served me as best they could these 45 years, past the nightmare of waking up intubated and weak. January 1 was a day of celebration – I am breathing, eating and walking my hospital-gown barely-covered bootie off. (The attempt to maintain one's dignity in this situation deserves another post.) Sending much gratitude out to all of you for your love and well wishes, to the medical and nursing teams here for their excellent care (ok, not 100%, as somehow pain management is still kicking its way out of the 20th century), and again to the boy whose beautiful pink lungs calmly give

me life.

Notes to self

January 7, 2013

Jerking awake and asleep, gasping, my body practically jumping up from bed during the transition between consciousness and unconsciousness.

E-mail communication

January 10, 2013

Surgical and medical teams both very happy with the outcome so far, but it has already been a difficult course with pain management and a complication. There's an air leak causing some tiny pneumothoraces and now subQ (subcutaneous) emphysema which has led my face – on top of the prednisone – to balloon to an incredible size, like a person wearing a fat suit. My skin from the waist up makes a crinkly sound when you press on it. The air leak led to me staying in ICU longer than expected, two weeks, but the last few days I was in ICU only because they didn't have a bed on the regular floor. Had four chest tubes to start with but two had to stay in for a prolonged period. The main problem with the chest tubes is pain, which I am feeling in my back directly behind where the incisions are; the pain can be excruciating but Demerol helps. I time my walks with the pain medicine schedule, because my back goes into spasm after I walk. Despite this I've gained a reputation for my marathon and speedy laps around the unit. I walk as much as I can.

Last night I had a nightmare that I was seizing and I woke up to find the bed was vibrating and there was a very loud noise – except the nurse was there and the noise and vibration were not – mostly my imagination – freaky scary – but not as scary as actually seizing, which is another potential post-transplant complication.

E-mail communication

February 7, 2013

Agh. I wound up going into full-blown withdrawal from my OxyContin and spent three days this week in the hospital, on top of 3-4 at home over the weekend with nausea, vomiting diarrhea, chills, sweats, aches, thrashing about…suffice it to say I did not taper gently enough.

> *"Like every adult with CF, my journey has been full of ups and downs, including the special time – the borrowed time, as I think of it – that I have lived beyond my transplant."*

Facebook post

February 18, 2013

Incredible rainbow over Debs Park last week (in our backyard!) that brought some needed cheer. Feeling much better today, after two and a half weeks of suffering withdrawal symptoms from going off my pain pills too quickly. Suffice it to say, it was a horrible time, and I lost so much weight that I could have fit into my Bat Mitzvah dress. This is not the good kind of weight loss – and note that despite me being overly thin, somehow the cellulite manages to hang on! Shouldn't the cellulite melt away first and then the curves? On the bright side, though I am weaker now than a few weeks ago, my lungs are still working GREAT, and I am working to build up my strength. In the meantime I am still re-learning how to sneeze! As many people know, I tend to sneeze in multiples, usually 5 or 7, and my new lungs apparently aren't yet coordinated enough with the rest of me for the ah and the choo part of each sneeze to automatically coordinate. By sneeze 4 or 5 it all starts falling apart and I sputter.

Thanks again all who are checking in on me and sending well wishes!

Facebook post

April 28, 2013

I can dance!

Notes to self

May 2013

It is shocking to me how little I can accomplish in a day and yet feel like my day has been completely full.

I feel changed. Or maybe I am not yet all recovered. My memory is terrible, my mind is soft.

I am still somewhat impatient with my progress.

I find it impossible not to feel that I am living on the edge. The edge of life and death. It can be an exciting place to be, because lots of things that people tend to take for granted feel like a thrill. The first time I ran errands, I was exhilarated to be out and about on a gorgeous Los Angeles spring day. I was so giddy, I managed to get a parking ticket. I am still enjoying these mundane things, grateful that I can park my car anywhere, knowing a stroll across the parking lot or down the block will be just fine. I won't have to stop and rest to catch my breath, I won't have to be carrying my oxygen tank cranked up to its maximum, timing myself so I don't run out of oxygen.

Continued on page 38

(The portable tanks only go up to 6 liters of flow per minute, and from January through December of 2012 I required 6 liters of oxygen to get out of bed, and sometimes 8 or 10 liters to shower.) I think sometimes now I walk around with a smile on my face (rather than my usual serious face) because I am just so happy to be alive.

The survival statistics following lung transplantation are slowly improving and there's no reason why I shouldn't be able to remain ahead of the curve, as I always have. That's what family and friends say and hope for and I hope for it too. But with recent statistics still showing that only 50% of people survive beyond five years, it is hard to escape that feeling of living on the edge.

E-mail communication

August 19, 2013

In early June, I developed a sinus and ear infection. That was the beginning of what turned out to be about six weeks of head-to-toe post-transplant issues. Because my lungs had multi-drug-resistant pseudomonas before the transplant, I was treated aggressively for the sinus infection and put on intravenous antibiotics – Zosyn, a drug I do not tolerate well but we've had to resort to. The horrible headache was better in a day but I felt like crap for the two weeks on the meds and beyond. Also I was very depressed to have a tube hanging out of me 24/7 again – I thought those days were behind me, and the thought of getting sick again freaked me out. I know the lungs will fail someday, and it is hard to bear the thought of again going into respiratory failure – the IV antibiotics brought it all back, like a trauma.

About a week after that, Adam and I went on vacation, up the California coast and to visit friends in the Bay Area. I wound up sick with food poisoning (twice? I had a 36-hour respite in the middle) and was incapacitated for four of our six days. It was a disaster. I'm talking, vomiting and sh*#ing on the side of the Pacific Coast Highway, not being able to leave the hotel room, an emergency room visit in Monterey, not even being able to see the friends we were trying to visit when they were only blocks away. The gastroenteritis resulted in something called post-infectious irritable bowel syndrome which left me uncomfortable, with nausea, poor appetite etc., for weeks. But now all better and appetite great!

SUSIE AND ADAM BALDWIN IN SEDONA, ARIZONA.

There was also a lot of fatigue involved with all this and I got off course with my exercise regimen and the gains I had made in strength. Turned out my white cell count was way low – they found it in the ER and then for a couple of weeks it kept dropping even though my pulmonary/transplant doc kept lowering my meds and even took me off one of the rejection meds altogether. I had another trip planned to San Fran for a big music festival (this was supposed to be a summer of fun before I went back to work) and could not go because I was too immunosuppressed.

While this was going on, they found a cyst/seroma in my pericardium, pressing into my right ventricle, which had to be worked up. The transplant surgeon (head of cardiothoracic at UCLA), cardiologist, pulmonologist, radiologists, have never seen this before in a transplant patient – apparently there are people who have this congenitally. Anyway, at this point it's okay, we're just going to watch it and repeat the cardiac MRI (a trip in itself – 90 minutes in the tube) in a few months. And I have an echocardiogram on Wednesday, but they don't know if they can see the cyst on that.

I'm anemic, kidney function borderline, chest still aches and my feet are numb all the time. And my insomnia is insane. However, on the bright side, I've had two menstrual periods during all this, which is rather exciting because I had stopped completely for 17 months. Never was happy about having a period before, but it's a sign that my body thinks it's healthy, and I find it reassuring. (But no plan for a baby at 46 – I'm sterilized with Essure!)

As of the last week am feeling like myself and energy coming back. I am optimistic and happy again.

To be continued…

Susie is 46 and is a physician who has CF.

treatment.
http://tinyurl.com/lok7lxv

Cystic fibrosis and pregnancy in the modern era: A case control study. Monica Ahluwalia, Jeffrey B. Hoag, Anas Hadeh, Marianne Ferrin, Denis Hadjiliadis. Journal of Cystic Fibrosis, Volume 13, Issue 1, Pages 69-73, January 2014

Pregnancy does not lead to immediate or medium-term adverse effects for CF patients.
http://tinyurl.com/mux723s

Rate of improvement of CF life expectancy exceeds that of general population—Observational death registration study. Matthew N. Hurley, Tricia M. McKeever, Andrew P. Prayle, Andrew W. Fogarty, Alan R. Smyth. Published online 13 January 2014.

The median age of death of people with CF is improving more rapidly than that of the general popula-tion in the U.S., England and Wales.
http://tinyurl.com/k9dufgl

Development of IgG antibodies to *Exophiala dermatitidis* is associated with inflammatory responses in patients with cystic fibrosis. Nahid Kondori, Anders Lindblad, Christina Welinder-Olsson, Christine Wennerås, Marita Gilljam. Journal of Cystic Fibrosis. Published online 16 January 2014.

The clinical importance of airway colonization by the fungus *Exophiala dermatitidis* in patients with CF is unclear. We have previously shown that *E. dermatitidis* frequently colonizes the airways of patients with CF. This study has found that *E. dermatitidis* triggers antibody production and may cause significant airway infection in patients with CF.
http://tinyurl.com/lmlrl66

Sinonasal manifestations of cystic fibrosis: A correlation between genotype and phenotype? M.C. Berkhout, C.J. van Rooden, E. Rijntjes, W.J. Fokkens, L.H. el Bouazzaoui, H.G.M. Heijerman. Journal of Cystic Fibrosis. Published online 07 November 2013.

Patients with CF are prone to develop sinonasal disease. The data from this study suggest more severe sinonasal disease in patients with class I–III mutations compared to patients with class IV–V mutations.
http://tinyurl.com/kgj4w7z

Quality of life is associated with physical activity and fitness in cystic fibrosis. Hebestreit H, Schmid K, Kieser S, Junge S, Ballmann M, Roth K, Hebestreit A, Schenk T, Schindler C, Posselt HG, Kriemler S. BMC Pulm Med. 2014 Feb 27;14(1):26

Health-related and disease-specific quality of life (HRQoL) was associated with physical fitness, especially aerobic fitness, and to a lesser extent with reported physical activity. These findings underline the importance of physical fitness for HRQoL in CF and provide an additional rationale for exercise testing in this population.
http://tinyurl.com/mlb3qre

Candidate markers associated with the probability of future pulmonary exacerbations in cystic fibrosis patients. Wojewodka G, De Sanctis JB, Bernier J, Bérubé J, Ahlgren HG, Gruber J, Landry J, Lands LC, Nguyen D, Rousseau S, Benedetti A, Matouk E, Radzioch D. PLoS One. 2014 Feb 12;9(2):e88567

Results demonstrate that worse clinical and Quality Of Life assessments during stable disease are potential markers associated with a higher risk of future pulmonary exacerbations, while higher levels of inflammatory markers at the end of antibiotic treatment may be associated with early re-exacerbation.
http://tinyurl.com/ozhs9sw

DIABETES

Early assessment of glucose abnormalities during continuous glucose monitoring associated with lung function impairment in cystic fibrosis patients. Leclercq A, Gauthier B, Rosner V, Weiss L, Moreau F, Constantinescu AA, Kessler R, Kessler L. Journal of Cystic Fibrosis, 2013 Dec 17

Cystic fibrosis-related diabetes (CFRD) is correlated with a decline in lung function. Under certain circumstances, oral glucose tolerance test (OGTT) screening, used to diagnose CFRD, fails to reveal early glucose tolerance abnormalities. In this situation, continuous glucose monitoring (CGM) could be a useful tool for evaluating early abnormalities of glucose tolerance in CF patients. The authors found that CGM reveals early abnormalities of glucose tolerance that remain undiagnosed by OGTT screening and are associated with worse lung function and a higher prevalence of P. aerugi-

Continued on page 40

In Memory

Anabel Mariko Stenzel, 41
Redwood City, CA
Died on September 22, 2013

James Edward Taylor, 41
Little Rock, AR
Died on December 29, 2013

Immediate family members may send in the names of CF adults who have died within the previous year for inclusion in "In Memory." Please send: name, age, address and date of death.
Send to:
CF Roundtable, PO Box 1618, Gresham OR 97030-0519.
E-mail to:
cfroundtable@usacfa.org

nosa colonization in patients with CF.
http://tinyurl.com/kychg2o

Simultaneous liver-pancreas transplantation for cystic fibrosis-related liver disease: A multi-center experience. Bandsma RH, Bozic MA, Fridell JA, Crull MH, Molleston J, Avitzur Y, Mozer-Glassberg Y, Gonzalez-Peralta RP, Hodik M, Fecteau A, de Angelis M, Durie P, Ng VL. Journal of Cystic Fibrosis. 2014 Jan 15.

Diabetes is associated with increased morbidity and mortality in patients with CF. While liver transplantation is well established for CF-related liver disease (CFLD), the role of simultaneous liver-pancreas transplantation is less understood. Patients with CFLD undergoing initial assessment for liver transplantation may benefit from consideration of simultaneous liver-pancreas transplantation.
http://tinyurl.com/m7md4k4

TREATMENTS

Hypersensitivity to antibiotics in patients with cystic fibrosis. Jobst Fridolin Roehmel, Carsten Schwarz, Anne Mehl, Philippe Stock, Doris Staab. Journal of Cystic Fibrosis. Volume 13, Issue 2, Pages 205-211, March 2014.

Hypersensitivity reactions to parenterally administered antibiotics (HRPA) are a substantial problem in managing CF. The authors conclude that during days 1 - 4 of antibiotic treatment patients are at elevated risk for HRPA. HRPA are drug-specific and dependent on cumulative annual exposure.
http://tinyurl.com/k9vokg4

Nebulized voriconazole in infections with *Scedosporium apiospermum*—Case report and review of the literature. J. Holle, M. Leichsenring, P.E. Meissner. Journal of Cystic Fibrosis. Published online 20 November 2013.

The authors report, for the first time, the safe and effective use of nebulized voriconazole for the treatment of severe pulmonary infection with *Scedosporium apiospermum* in an adolescent with CF.
http://tinyurl.com/ke5ynuv

Inhaled aztreonam for chronic *Burkholderia* infection in cystic fibrosis: A placebo-controlled trial. D. Elizabeth Tullis, Jane L. Burns, George Z. Retsch-Bogart, Mark Bresnik, Noreen R. Henig, Sandra A. Lewis, John J. LiPuma. Journal of Cystic Fibrosis. Published online 31 October 2013.

24-weeks of continuous AZLI treatment did not significantly improve lung function in CF subjects with chronic *Burkholderia spp.* infection.
http://tinyurl.com/lcr74un

Antibacterial properties of the CFTR potentiator ivacaftor. Leah R. Reznikov, Mahmoud H. Abou Alaiwa, Cassie L. Dohrn, Nick D. Gansemer, Daniel J. Diekema, David A. Stoltz, Michael J. Welsh. Journal of Cystic Fibrosis. Published online 07 March 2014.

Ivacaftor increases CFTR channel activity and improves pulmonary function for individuals bearing a *G551D* mutation. Because ivacaftor structurally resembles quinolone antibiotics, the authors tested the hypothesis that ivacaftor possesses antibacterial properties. The data indicate that ivacaftor exhibits antibacterial properties and raise the intriguing possibility that ivacaftor might have an antibiotic effect in people with CF.
http://tinyurl.com/m8ou99m

Sinonasal inhalation of dornase alfa administered by vibrating aerosol to cystic fibrosis patients: A double-blind placebo-controlled cross-over trial. Jochen G. Mainz, Claudia Schien, Isabella Schiller, Katja Schädlich, Assen Koitschev, Christiane Koitschev, Joachim Riethmüller, Uta Graepler-

Continued on page 42

BYRNES *continued from page 11*

Overall, though positive thinking is socially accepted and encouraged and all studies point to the fact that it's good for you, when we are down in the dumps we have the right to feel it, say it and live it. It's called being real, being human, being spiritually authentic. The scale of negativity will sometimes outweigh the weight of the positive. I have to acknowledge that some chapters of the CF experience are so horrendous, there is nothing positive to compare to at all – for example, the death of a loved one, a transplant surgery gone awry or a terrifying lung bleed. Those difficult experiences need to be dealt with as a crisis and trauma, and small glimpses of something positive may or may not come after much time has passed. For most other routine challenges in CF, I believe practicing mindfulness – non-judgmental awareness and acceptance – can help us to deal with our negative emotions. Reminding ourselves of all the resilient ways we have coped with past negative emotions can be helpful as well. When it is needed, balancing the tough emotions that come our way with positive thinking, such as shifting perspectives or practicing gratitude, can help us not get stuck in despair. Getting stuck makes it harder to see any other perspective, and makes CF a much harder disease than it needs to be. We have enough to deal with!

Isabel Stenzel Byrnes is 42 and has CF. She lives in Redwood City, CA, with her husband, Andrew. You may contact her at: isabear27@hotmail.com.

Encourage Family and Friends to Sign Donor Cards

Give the gift of life that lives after you.

To receive donor cards, call:
United Network For Organ Sharing 1-800-355-7427

Calling All Writers

Have you written an article or story for *CF Roundtable?* If not, why haven't you written? Are you concerned that you may not be a great writer? Don't let that stop you. We have people who will work with you, on your article, to make it the best it can be.

Are you concerned because you can't think of a topic? How about if we give you a few ideas to start with? Here are some titles that go from head to toe and might pique your interest to write. Remember, these are only suggestions. You may come up with entirely different ideas and that is fine with us. All we ask is that you write about your experience with CF.

Here are a few possible topics for your use: headaches; understanding what you hear; pain(s) in the neck; arm twisting; the case at hand; a breath of fresh air; gut reaction(s); pain in the butt; oh, my aching back; getting hip to a subject; standing on one's own two legs; at the foot of the problem; toeing the line; my sole responsibility. As you can see, these are humorous suggestions that are meant to give you some ideas. You need not use any of these, but you may, if you wish. For other ideas, check out the Looking Ahead section on page 3. All submission dates for the coming year are posted there.

We ask that all submissions be typewritten. If you want to e-mail your submission, please have it in Microsoft Word or a similar program. You may send your submissions to: cfroundtable@usacfa.com
or to
USACFA
PO Box 1618
Gresham, OR 97030-0519.

Mainka, Bärbel Wiedemann, James F. Beck. Journal of Cystic Fibrosis. Published online 04 March 2014

Chronic rhinosinusitis significantly impairs CF patients' quality of life and overall health. The Pari-Sinus™ device delivers vibrating aerosol effectively to paranasal sinuses. This study shows that vibrating sinonasal inhalation of dornase alfa reduces rhinosinusitis symptoms in CF.
http://tinyurl.com/kkqlead

Tobramycin inhalation powder in cystic fibrosis patients: response by age group. Geller DE, Nasr SZ, Piggott S, He E, Angyalosi G, Higgins M. Respiratory Care. 2014 Mar;59(3):388-98.

Tobramycin powder for inhalation (TIP) is a drug–device combination designed to reduce treatment time and improve ease of use compared with tobramycin inhalation solution (TIS) in CF patients. However, the ability of patients to use dry powder inhalers, and the efficacy of the treatments, may vary by age. TIP is comparable to TIS in efficacy outcomes and safety profile but had greater patient satisfaction in all the age groups.
http://tinyurl.com/mbxd4y9

Laura is 66 and has CF. She is a Director of USACFA and is the President. Her contact information is on page 2.

▲

If you would like previous issues of *CF Roundtable*, e-mail us at: cfroundtable@usacfa.org to request PDFs of back issues. Or, if you are an online subscriber, please go to the link for that page to download issues from 2008 to present. They are free to everyone. Previous editions and their Focus topics are listed below:

Past CF Roundtable Focus Topics

2014
Vol XXIV No. 2: Maintaining Mental Health (current)
Vol XXIV No. 1: Memory Problems

2013
Vol XXIII No. 4: Living with Pain
Vol XXIII No. 3: Who or What Keeps You Going?
Vol XXIII No. 2: Gastrointestinal Issues
Vol XXIII No. 1: Osteoporosis, Osteopenia and Other Skeletal Issues

2012
Vol. XXII No. 4: Organ Transplant - Has It Met My Expectations?
Vol. XXII No. 3: Respiratory Therapy Activities
Vol. XXII No. 2: Are You An Optimist or a Pessimist?
Vol. XXII No. 1: Our Pets and How They Affect Our Lives

2011
Vol. XXI No. 4: CF, It's Not Just for Children
Vol. XXI No. 3: If Only I Had Known Then What I Know Now
Vol. XXI No. 2: Hobbies and Pleasure Activities
Vol. XXI No. 1: Sleep or Lack of It

2010
Vol. XX No. 4: Choosing the Right Caregivers
Vol. XX No. 3: All Types of Support
Vol. XX No. 2: Traveling For Work or Pleasure with CF
Vol. XX No. 1: Diet and Nutrition

2009
Vol. XIX No. 4: Gender-related Problems in CF
Vol. XIX No. 3: Becoming a Parent with CF
Vol. XIX No. 2: Making Career Choices with CF
Vol. XIX No. 1: Love, Dating and Marriage

2008
Vol. XVIII No. 4: Organ Transplants
Vol. XVIII No. 3: New Products and Equipment that Make Our Lives Easier
Vol. XVIII No. 2: Traveling With CF
Vol. XVIII No. 1: The Power of Positive Thinking

2007
Vol. XVII No. 4: Finding CF Support Through Technology
Vol. XVII No.3: Having CF When You Are Part of a Minority Population Group
Vol. XVII No.2: Dealing With the Limitations of CF
Vol. XVII No.1: Changes to Major Organ Functions, Organ Failures, and Organ Transplants

2006
Vol. XVI No. 4: Transitions – Forgiveness, School-to-Career-to-Retirement, Anticipatory Grief, Survivor Guilt, and Other Transitions in Our Lives.
Vol. XVI No. 3: Proper Care of Our Equipment
Vol. XVI No. 2: Traveling With Cystic Fibrosis
Vol. XVI No. 1: Being Secretive About Our CF

CF ROUNDTABLE SUBSCRIPTION FORM (Please Print Clearly)

PLEASE CHECK ONE: ☐ **NEW SUBSCRIPTION** **OR** ☐ **UPDATE**

NAME _____ **PHONE (** **)** _____

ADDRESS _____

CITY _____ **STATE** _____ **ZIP+4** _____ **+** _____

E-mail address: _____

I am interested in CF Roundtable because I am a: CF ADULT _____ BIRTHDATE _____

OR I am a: Parent ____ Relative ____ Friend ____ Medical/Research Professional ____ Caregiver ____

CF Roundtable is available at no cost. However, to help defray printing and mailing costs, donations are always welcome.

- Donation to defray costs . . . . . $ _____
- Please send me the back issues I have listed on a separate sheet of paper.
- Please send subscriptions to the names and addresses I have listed on a separate sheet of paper.

Please do not write in this space

SP 14

For donations, make checks payable to USACFA and mail with this completed form to:
USACFA, P.O. Box 1618, Gresham, OR 97030-0519
We ask that everyone keep their home and e-mail address information up to date.

OR

You can also subscribe online! Go to www.cfroundtable.com. You can now scan this QR Code with your smart phone to go directly to our online registration page. By subscribing online you have the ability to download a PDF of the latest newsletter, receive the mailed version or you can receive both. The online version will be available two weeks prior to the mailed version.

KEEPING YOUR INFORMATION CURRENT

To keep our records up to date, please be sure to complete and return a subscription form, on this page, to us or register online with any changes to your information, www.cfroundtable.com. (Any issue of the newsletter that is returned to us costs us about two-and-a-half times the first-class postage rate for that piece. Currently that runs about $3.73 per returned copy.) **Thank you for helping us with this.**

Be sure to check us out on:

Twitter: http://twitter.com/#!/cfroundtable
Facebook: http://www.facebook.com/CFRoundtable
Blogspot: http://www.cfroundtable.com/blog-2/

REMINDERS

- Please notify us immediately of any address changes. Returned mail wastes money and delays mailings.
- We would like to act as a referral source for active adult support groups. Please send us your group name, leader's name and phone number, number and age range of your members and geographical area covered, and we will add you to our referral list.
- Please let us know of the major occurrences in your life (*e.g.*, *marriages*, *births*, *completion of educational degrees or training*, *career advancement*, *transplants*, *anniversaries*, *birthdays*) and we will print your information in **Milestones**.
- Share your ideas for **Focus Topics**, feature articles or any suggestions for improvements you may have to help make *CF Roundtable* more relevant and interesting to you.
- You can reach **USACFA** and ***CF Roundtable*** at anytime by phone **(248) 349-4553**. You may e-mail us at **cfroundtable@usacfa.org**
- Send your questions of a general nature regarding legal issues that relate to CF to our legal advisor: **Beth Sufian, Esq., 712 Main, Suite 2130, Houston, Texas 77005. E-mail: CFLegal@sufianpassamano.com.**
- You may subscribe at www.cfroundtable.com

Published by the United States Adult Cystic Fibrosis Association, Inc.
CF Roundtable is printed on recycled paper.

IMPORTANT RESOURCES

Partnership for Prescription Assistance: Phone: 1-888-477-2669 http://www.pparx.org/prescription_assistance_programs
The Partnership for Prescription Assistance brings together America's pharmaceutical companies, doctors, other health care providers, patient advocacy organizations and community groups to help qualifying patients without prescription drug coverage get free or low-cost medicines through the public or private program that's right for them.

United Network for Organ Sharing (UNOS): Phone: 1-888-894-6361 http://www.unos.org/
Call for information on transplant centers, access for all patients needing organ transplants and general transplant information.

Transplant Recipients International Organization, Inc. (TRIO): Phone: 1-800-TRIO-386 http://www.trioweb.org/index.shtml
An independent, nonprofit, international organization committed to improving the quality of life of transplant recipients and their families and the families of organ and tissue donors. For information, write to: TRIO, 2100 M Street NW, #170-353, Washington, DC 20037-1233 or e-mail them at: info@trioweb.org.

American Organ Transplant Association (AOTA): Phone: 1-713-344-2402 http://aotaonline.org/default.aspx
Helps defray out-of-pocket travel expenses for transplant recipients. Helps to set up trust funds. For more information, write to: AOTA, 21175 Tomball Parkway #194, Houston, TX 77070-1655.

ADA: To learn how the American with Disabilities Act (ADA) applies to you, contact the Disability Rights Education and Defense Fund (DREDF): Phone: 1-800-348-4232 http://www.dredf.org/.