CF Roundtable
A NEWSLETTER FOR ADULTS WHO HAVE CYSTIC FIBROSIS WINTER 2011

To Sleep, Perchance to...

By Kathy Russell

When I first saw the Focus topic for this issue, "Sleep Or The Lack Of It", I thought that I had nothing to say about it. Then I started to think and realized that there are some comments I can make. When I was working swing shift (evenings, to some of you) I would come home, watch a little TV while eating a snack and then go to bed. I definitely was tired, but often I found it difficult to sleep. I was so tired that I couldn't relax.

After I went to sleep, I would twitch and jerk. My legs would jump and wake me. I would dream that I was falling and that would wake me. Often, I would relive my entire eight hour shift in my sleep. I would wake up almost as tired as I had been before I went to sleep. It was a little like a minor form of PTSD. It took a while but, eventually, I learned how to sleep without reliving my day. I had to learn that what was done was done and there was no sense in reliving it.

I never used any kind of sleeping medicine. I didn't want to get into that habit. I always have avoided taking any medicines that are not vitally important to my health. I am not a fan of taking medicines and I never have wanted to get used to using chemicals for regulating my body.

KATHY RUSSELL

Once I stopped working, I found that I had almost no problems with sleeping. I went to bed when I was tired and I arose when I was rested. Of course, there still are nights when I find it hard to get to sleep. Maybe my oxygen is whistling in my head, or I am too hot or too cold, or my pillow feels too hard or too soft, or any other of a whole litany of complaints that my mind can conjure. When that happens, I just figure that I will have to "catch up" on my sleep on another night and I don't let it bother me.

I know, you're thinking that it's easy for me to "not let it bother" me, since I don't have to get up for work the next day. You're right; it is easy for me. That is just one of the advantages of getting old. Since I am able to fall asleep almost anywhere, I feel that I do catch up...most likely in front of the TV the next evening.

I find that I am so tired, most

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INSIDE THIS ISSUE

CF ROUNDTABLE
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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 or FAX (503) 669-3561
E-mail: cfroundtable@usacfa.org
www.cfroundtable.com

EDITOR'S NOTES

I hope everyone celebrated a happy and healthy new year. Unfortunately, this time of year brings colds and the flu. It seems everyone around me is coughing or blowing a nose, and that is just in my home! I jest. I try to stay as healthy as possible by washing my hands frequently, especially when I get home, to avoid bacteria and germs from outside. And I try getting as much sleep as I can.

Sleep is said to be an important immune booster and it is our Focus topic for this issue. **Paul Feld** loves to sleep. In his article, he mentions that consistent sleep patterns tend to provide the best sleep. In my article, I discuss the importance of napping; its pros and cons. In *A Deep Breath In*, **Debbie Ajini** writes about her need for sleep and shares her pre-bedtime regimen, in the hopes of helping others get a good night's rest, too.

Another common thread in this issue is inspiration or positivity. In *Spirit Medicine*, **Isa Stenzel Byrnes** writes about different ways of looking at the inspirational, its roots and what it means to her. **Julie Desch,** in her *Wellness* column, shares her experience of loss from the past year and how she is getting through it by using resiliency and positive psychology. In *Voices from the Roundtable*, **Jason Egbert** shares his winning submission on what inspires him to pursue his dreams. He was the winner of $18,000 for post-high school education. Truly inspiring.

In *Ask the Attorney*, **Beth Sufian** writes a top ten list to assist people to get along with their CF Care Centers better. **Mike Hale,** in *Voices from the Roundtable*, writes about juggling insurance issues while trying to work with a disability. We are fortunate to have two poems in this issue. First we have **Nicole Matthews,** who wrote "My Poem, My Life" about living with CF. Second is **Jennifer Mackey,** who writes about her personal experience with abusive patterns and relationships. She shares a poem in that vein called, "Your Nothing".

For new information on treatments and news on CF, please check on page 13 for *Information from the Internet* compiled by **Laura Tillman.** On page 26, a good resource to help pay for medications is *Patient Assistance Programs and Other Resources*.

We, at USACFA, want to bring you the best publication we can. To facilitate that, we ask that you take note of a few new announcements. On page 3, *Clarification of USACFA Publishing Policies* will illuminate our purpose and priority in publishing practices. On page 25, *New Donor Designations* are aimed at rewarding sustaining partners for their valued support. Which brings us to page 31 and subscription changes. For 20 years, we had requested the same amount for annual donations, but due to costs of printing and mailing, which all have gone ever skyward; we are requesting a slightly larger annual donation amount.

Please continue to share your lives with us with Milestones, poems, articles or suggestions. We hope to continue to bring you the best newsletter possible.

Thank you!
Andrea Eisenman

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Important News

Clarification of USACFA Publishing Policies

It has come to our attention that some people do not understand the publishing policies of *CF Roundtable*. Since we began publishing, in 1990, we have made it a priority to publish articles that are written by adults who have CF. If there is room, after publishing all of those articles, we might publish something by a person who doesn't have CF.

There have been occasions where we have published something that was written by someone who didn't have CF. Usually, those items were of special interest to adults who have CF and were not easily accessed anywhere else. Also, when we had a Focus topic that was especially for family members or caregivers, we published articles by those groups. A few times we have requested that a non-CF person write about a specific topic for us. Those writers have included parents of adults with CF, physicians and other medical people.

We hope you understand that *CF Roundtable* is aimed at adults who have CF. That is our primary focus and those are the people to whom we cater. If there is room, if an article has information that is not readily available elsewhere and if we feel that the information contained in the article is of importance to adults who have CF, we will try to publish it.

We do not carry advertising and we will not publish anything that is primarily an advertisement for any service or product. We still will publish stories that are written by adults who have CF who are relating their experiences with a piece of equipment or a particular treatment.

We hope this will clear up any confusion there may have been about what our publishing policies are.

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 topics you might like writing about. In addition, humorous stories, articles on basic life experiences, short stories, art work, cartoons, and poetry would be greatly appreciated. We require that all submissions be original and unpublished. With your submission, please include a photo of yourself (as recent as possible) 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**

Winter (current) 2011: Sleep Or The Lack Of It.

Spring (May) 2011: Hobbies And Pleasure Activities. (Submissions due March 15, 2011.) What do you do to fill your time? Do you create something such as: jewelry, art, sewing, woodworking or stained glass? Do you read or play sports or travel? Are puzzles (jigsaw, crossword or other kinds) your passion? Tell us what you have found to make your time productive.

Summer (August) 2011: If Only I Had Known Then What I Know Now. (Submissions due June 15, 2011.) Do you find that there are things that you have learned along the way that could have made your life easier? Are there tips that you can share with our readers? What are some of the "must know" facts about living with CF or things that you wish you had known when you were younger?

Autumn (November) 2011: CF, It's Not Just For Children. (Submissions due September 15, 2011.)

ASK THE ATTORNEY

Top Ten Tips for Working With One's CF Care Team

By Beth Sufian, Esq.

This column is a top ten list of things that may help a person get along with his or her CF Care Center team (CF team). I have received 10 questions in the past three months from people with CF who asked about ways to resolve conflicts with a member of the CF team. Some of the questions related to personality conflicts, others to disagreements related to prescribed treatments or accessibility of a physician.

In most areas of the country there is only one CF Adult Care Center in a specific city and typically there are only one or two CF Adult Care Centers in an entire state. The limited number of physicians who are specially trained in the care of adults with CF means that most adults with CF have to learn to get along with the CF Adult Care Center team that is located nearest their home. Hopefully some of the issues raised in this column may help to foster a better understanding between adults with CF and their healthcare providers.

Nothing in this column is meant to be legal advice about your specific situation. If you have questions, please contact the CF Legal Information Hotline at 1-800-622-0385. The Hotline provides free and confidential legal information to people with CF, their families and their CF Center care teams. The Hotline is proudly sponsored through a grant from the CF Foundation. The Hotline also can be reached by e-mail at CFlegal@cff.org.

Number 10

Contact the Appropriate Person or Agency

There sometimes are situations that arise in the receipt of medical care that may necessitate filing a complaint about substandard care. All hospitals should have an "Office of Patient Services" and patient advocates whose job it is to help advocate for patients who have issues related to their care. If a patient has a complaint or has received substandard care, the Patient Services office may be able to help resolve the issue. In addition, all states have accrediting agencies for a variety of healthcare workers. There should be accrediting agencies for physicians, nurses, physical therapists, pharmacists and other healthcare workers. If there is a violation of a healthcare provider's duties, a patient may file a complaint with the appropriate agency. Filing a complaint is a serious matter and should not be taken lightly. In appropriate situations, filing a complaint may lead to a change in unsafe practices in a healthcare setting.

Every state has its own laws that regulate medical malpractice. Most

BETH SUFIAN

states have limits on the amount of money a person bringing a lawsuit for medical malpractice can recover. A medical malpractice attorney should be consulted to determine if a specific claim has merit. A medical malpractice case is not a lottery ticket. There are very few attorneys who handle medical malpractice cases, because in most states there is limited recovery and the cases are difficult to win.

Number 9

Have Realistic Expectations-Take Something to Read.

I am always surprised when I speak to people with CF who complain about having to wait to see the physician at a clinic visit. When I go to a clinic visit I plan to be there for a while. I bring a book to read and some work to do while I wait. I do not mind waiting. I know that if I need to be worked into the schedule in the future it will result in other people waiting to see the doctor and that makes waiting much easier.

The time I wait is never as long as the amount of time I waited to see the doctor when I was a child. When I was diagnosed, in 1974, my CF physician was the only CF specialist in a 10-state radius. Most of the patients traveled long distances to see the CF doctor and were extremely sick. At that time there was no Pulmozyme, Cayston, TOBI, Hypertonic Saline, Vest, enzymes and very few IV antibiotics.

My mother would take my sister and me to see the doctor every six months for a checkup. We would

Our biggest selling point to recruit pulmonologists to adult care is the people who have CF.

cough all the time and were extremely thin, but compared to the doctor's other patients we were considered healthy. Typically, we would wait 6-8 hours to see the doctor. Yes, you read that right, 6-8 hours waiting. After we were seen we would get 25 cents to spend in the hospital gift shop. We spent hours looking at the items for sale trying to decide what we would buy after we saw the doctor.

My mother packed a lunch which we ate sitting on folding chairs in the hallway because there was no waiting room. The CF Care Center was at a rehabilitation hospital and in the halls there were many people who were in wheelchairs and who had missing limbs. My mother would tell us how lucky we were to have CF. My mother never complained about the wait and so my sister and I did not complain. My mother also always told us that we had to wait because the doctor was taking care of children who were much sicker than we were and that we should be thankful we had to wait because that meant that we were not very sick.

Moral of the story - plan on waiting and remember that your time spent waiting means your doctor is helping someone who is more in need of her help at that moment. Other moral of the story - if you find yourself whining about having to spend time doing treatments, think about a time when parents would have given everything they had for a medicine that could treat the bacteria in their children's lungs or make it easier for their children to clear the thick mucous that made it so difficult to breathe. It is amazing how much you appreciate doing treatments when you remember a time when there were no treatments for CF.

Number 8

Understand that Treating Adults with CF is Difficult

It is hard to find adult pulmonologists who will commit to treating adults with CF at a CF Adult Care Center. The CF community needs to understand how difficult it is to recruit adult pulmonologists to specialize in the care of adults with CF. The CF Foundation has been trying for many years to find ways to attract pulmonologists to take care of adults with CF, but it is an uphill battle. If you ask adult pulmonologists why they do not want to become CF specialists, many will tell you that the disease is too complex and that the patients require a lot of time.

The pulmonologists who decide to treat adults with CF often tell a story of having come in contact with one or more adults with CF and enjoying the experience of getting to know such special people. Our biggest selling point to recruit pulmonologists to adult care is the people who have CF. Most people with CF value their healthcare provider's care and dedication. Some physicians who leave CF adult care often cite a few patients who were so difficult it became impossible for the physician to treat the majority of his patients. Make sure you are not the patient that drives an adult pulmonologist out of CF care. Treat your CF team with respect and be thankful that the physician and other CF team members have chosen to focus their time on treating adults with CF.

Number 7

A CF Physician is Not a Personal Slave

Some people with CF expect their physicians to be available 24 hours a day, 365 days a year. Remember, physicians are people, not slaves. CF physicians have families and friends. An expectation that one physician will be on call for a patient's every need all day, every day is not realistic. Frankly, I do not want 24-hour access to my physician. First, I want him to be able to spend time with his family or friends and to have some other personal interests besides treating people with CF. Second, I know that there are patients who are dealing with more complex health issues than I am and I want my physician to treat those patients instead of taking my calls asking if I should start Cipro for a sinus infection.

Of course, I want to be able to contact a physician in an emergency, but I understand that a physician may not be my usual CF physician. Every CF Adult Care Center has one or more knowledgeable nurses who can discuss health concerns with patients and relay questions to the physician. Utilize all members of your CF care team and do not expect to be able to reach your physician any time you have a question.

I do not mind my physician taking a call while I am meeting with her, if it is an emergency. However, I would mind if every few minutes my clinic visit was interrupted by a patient who wants 24-hour access to the physician. Patients who understand how to use the other members of the CF care team will receive quicker responses to their questions. Remember you are not the only patient your physician is treating. Realistic expectation is the name of the game.

Continued on page 10

SPIRIT MEDICINE

In-Spirit-ational

By Isabel Stenzel Byrnes

For many years now, each time I do something like compete at the Transplant Games or do public speaking for CF, inevitably, I am approached by someone who says, "You're such an inspiration."

After hearing it over and over again, I'd automatically cringe, rather than feel complimented. Since I sincerely know people say this with good intentions, I'd politely thank the inspired but feel phony. In this Spirit Medicine article, I thought I'd muse on exactly what "being an inspiration" means to me.

On face value, being inspired means to believe in something and/or want to do something that you didn't know about, believe or want to do before being inspired. Inspiration can mean both emotional compulsion and a lofty purpose. For example, watching the movie, *Food, Inc.*, inspired me to eat organic and not drink from disposable water bottles. Being inspired means making me want to be a better person.

I struggle when people perceive me as inspirational because I happen to have cystic fibrosis or a lung transplant. It feels patronizing. As my friend Anna boldly responds to those who call her inspirational, "Well, if you were sick and dying, you'd be inspirational too!" I would rather be inspiring based on who I am or what I've contributed to the world, rather than just because of my CF, or because I do things *and I* have CF.

Thanks to my CF friends, especially those on the Facebook CFer group, I learned many people with CF are called 'inspirational'. While most of these friends feel they're just living their lives, they have shared what it means "to be an inspiration". Tom says he is inspirational because of his powerful imagination— he visualizes all the possibilities of what his dreams are— and then goes out and tries to realize his dreams. Eric says, "People are inspired by my thoughts and actions to do what they think isn't possible for themselves." He also says, "It can be a burden, too. I don't live up to their perception of being an inspiration, I have somehow failed them. People put me on a pedestal and expect me to live a certain way in order to keep that perception alive." Maggie also says, "Our society has to look up to others or find heroes. People see the sick as inspirational because we do something they don't think they can do themselves. I see it as working a bit harder to be on this earth, but if I'm inspiring people by hacking up a lung each day and night, then so be it!" I completely agree that people can't imagine themselves happy or content with life if they had a labor-intensive terminal illness, so they admire those who can do that.

> *"Sometimes to be inspired means witnessing great resilience, and storing that spiritual energy inside for the times one might need it in the future."*

ISA STENZEL BYRNES

I'm working on how to accept the praise of being an inspiration with less cynicism. One approach is to go back to the fundamental definition of this word, which is relevant to people with cystic fibrosis. To *inspire* literally means to breathe in, to inhale. We breathe in motivation, strength, and influence when someone inspires us. According to Merriam-Webster, the first definition of 'inspire' is: "to influence, move, or guide by divine or supernatural inspiration." I never thought of it that way. I now understand that 'inspiration' is a spiritual act. It does, after all, include two words: in + spirit. In the Bible (2 Timothy 3:16), the words "God-breathed" are used to connote the meaning of 'inspiration.' Inspired

writings were "breathed out" by God. After all, the word 'spirit' in Greek is '*pneuma*' or 'breath.' When someone is being inspirational, he/she is truly 'in spirit'— living out the life they are given, finding grace, strength, passion, determination, hope, talent—even God inside themselves. The spirit may shine brighter and stronger when there is unrelenting challenge or hardship, like CF. When a person witnessing something remarkable or impressive is inspired, they receive some of that spiritual gift.

To feel inspired can be a physical sensation, such as heart palpitations, a jaw drop, a deep breath in or a "*Wooooowww*" breath out. It can be a conviction, "I want to be like that." Being inspired can also trigger a strong emotional reaction. Several months ago, I attended a multicultural transplant meeting. At the reception, a group of flamenco dancers entertained us. The leader was a Latino man who had had a double lung transplant. He danced energetically with a glow on his face, sporting a massive grin. To the music, he flung his arms and legs freely around with ease, and I found myself tearing up uncontrollably. For a moment it was like I was dancing. I was fully alive with him, celebrating his breath. I was enjoying the pure bliss and passion that he felt, dancing with his new lungs. I felt a connection. This man's spirit was exploding outside of him, and I was catching it. I was reflecting his spirit with my reaction.

Sometimes to be inspired means witnessing great resilience and storing that spiritual energy inside for the times one might need it in the future. Last month, I found myself hiking in Denver with my post-transplant friend with CF, Missy, who suffers from chronic rejection. She used 5 liters of oxygen to make it to the top of a glacier at 10,000 feet. I asked her if she was okay, if she wanted to stop, should we be doing this; but slowly and deliberately she put one foot in front of the other, did pursed lip breathing, and just kept going—with a smile on her face the entire time. She'd crank up the oxygen during really steep parts. She panted. She sweat. But she wouldn't give up. She wouldn't let panic or air hunger stop her. Her iron will was bursting out of her. As someone post-transplant, I may find myself with damaged lungs again someday. I want to be like her when I'm in that state. Missy set out to do something she wanted to do, and proved she could achieve her goal. With her heavy breathing up the mountain, she was breathing in and out her defiant spirit. I was truly inspired.

Missy said one more thing: "When people tell me I'm an inspiration to them, it feels good. I know I'm living out the plan that was meant for me." Her role as an inspiration in the eyes of others is seen as predestined for her. It was like God wanted her on top of that mountain, and I was to be the witness. This makes me believe that all the spiritual energy that we pass on to each other and share is from a force much larger than ourselves. I alone cannot deny or decry being an inspiration or being inspired.

So, now I've made a decision to try to gracefully accept being an inspiration to those who need a piece of spiritual energy. Maybe I am fulfilling something sacred that people are seeking. I am "in-spirit-ational". I gladly pass on the force inside of me that I've received from so many of my CF and non-CF friends. It's my obligation to be the spiritual messenger. My hope is that you, too, can also be in-spirit-ational and share your spirit, your drive, your passion with those who need enrichment. ▲

Isabel is 38 and has CF. She lives in Redwood City, CA. You may contact her at: Isabel@usacfa.org.

Announcements

VOLUNTEERS NEEDED FOR STUDIES AT NIH

The Pulmonary-Critical Care Medicine Branch of the Department of Health & Human Services, National Institutes of Health(NIH), National Heart, Lung, and Blood Institute, in Bethesda, Maryland is conducting **a research study to evaluate the role of bacterial products involved in lung disease in cystic fibrosis.** We are looking for individuals with cystic fibrosis and Pseudomonas aeruginosa. The participants will be seen at the NIH. They will have blood drawn (around 2 tablespoons) and also have a sputum sample collected. The participants with CF will be paid $50.00 for taking part in this study. We will pay for the transportation of patients who do not live in the local area. If you have CF, are at least 18 years old, have Pseudomonas aeruginosa and are interested in more information about this study, please call us collect at (301) 496-3632 or send E-mail to: barnesp@nih.gov.

A research study of hereditary factors associated with cystic fibrosis and other lung diseases is being conducted at the Department of Health & Human Services, National Institutes of Health (NIH), National Heart, Lung, and Blood Institute in Bethesda, Maryland. Participants will be admitted for an overnight stay at the NIH to have blood drawn, a PFT, chest x-rays, and EKG. Assistance with travel costs as well as a $150 stipend will be provided. If you have CF, are 18 years of age or older, and are interested in participating in this study, please call us collect at (301) 496-3632, or send E-mail to: barnesp@nih.gov.

We are looking for individuals with cystic fibrosis who previously participated in NIH studies. If you have taken part in an NIH study, please call the toll free number: 1-877-644-5864 and select #3 on the menu; or send an E-mail to: barnesp@nih.gov.

Inspired to Achieve

By Jason Egbert

At age 24, I'm still learning how to balance the challenges of everyday life while pursuing a career in optometry. Although having cystic fibrosis (CF) makes it even more complicated, I've learned how to manage it in a positive way, by gaining inspiration and strength from everyone and everything around me. With the support of my beautiful wife, I'm well on my way to reaching my dreams of being a doctor.

To help me reach my goal, earlier this year I decided to apply for the CFCareForward Scholarship Thriving Student Achiever award, an Abbott patient-support program. The scholarship program offers $18,000 to motivated students with CF who are pursuing post-high school education. As part of the submission process, I was asked to write an essay based on one simple question: "Who or what inspires you to pursue your dreams?"

It wasn't until I sat down to write the essay that it occurred to me: a lot of things inspire me, even the obstacles I face every day. As a result of this inspiration, and continuous support from my wife, family and friends, this fall I was awarded the 2010 CFCareForward Thriving Student Achiever Scholarship. Having the opportunity to apply to this scholarship program has been an amazing experience, and it is something I would encourage anyone with CF who is pursuing higher education to be a part of next year.

Here is my winning submission:

"Who or what inspires you to pursue your dreams?"

Inspiration is the driving force to do good and to become better

This is what inspires me

Married couples in their 90s that still hold hands

Painless breaths of fresh air

The underdog

Friends that push me to be better

Seeing others succeed

Cinderella Man

A good, clean joke

A pretty clean, dirty joke

Simple acts of kindness

Doctors and nurses that smile at me and call me by name

My wife's love and continual encouragement

Just kidding about the dirty joke thing

Michael J. Fox

A good challenge

When other people believe in me

Integrity, courage, sacrifice, loyalty

Advancements in medical research

Checking out of the hospital

High expectations

Cystic fibrosis patients in their 60s

Good music

Family, coaches and teachers

Acing a test

New babies

Accomplishing goals

Dr. Seuss

Good memories

The strength that comes from my faith in God

Jason is 24 and has CF. He is a student at the Southern California School of Optometry.

evenings when I go to bed, that I have very little trouble falling asleep. If I am having a little trouble, I think about the past 20 years of working on *CF Roundtable*. I remember people with whom I have talked, some whom I've met, some who have become like family to us, some who have died, some who are fighting an infection or rejection, others who are thriving and doing things that sound terrific, and all the wonderful stories that I have read in the newsletter. I find that remembering these things makes me happy and allows me to rest well.

When we began USACFA and *CF Roundtable*, we hoped that it would flourish. Somehow, I feel that it has gone far beyond our wildest dreams. We have published 20 volumes of four copies each. This issue begins our 21st year of publishing. We still are able to publish a newsletter that is made up almost entirely of articles and other items from adults who have CF. (We do, occasionally, publish something from a person who doesn't have CF, but those times are rare.) We still have no paid employees and get no government subsidies. We are fortunate enough to receive some generous grants from a few corporations and some generous donations from many of our readers. Those donated monies have allowed us to continue publishing a newsletter that is full of articles and other items that are done by adults who have CF and are of interest to people who have an interest in CF.

Any time that someone comments on how much he or she appreciates *CF Roundtable*, I realize all over again how much I get out of volunteering on this newsletter. Since the spring of 1990, I have dedicated many hours each week to helping to make sure that we make the best newsletter that we can. I have been with USACFA longer than I was at any paid job. If I had invested this much time and energy into a paid job, I could retire with a nice pension. Instead, I have a collection of many friends who are better than any pension ever could be.

The dreams for USACFA continue to grow. Currently, we are working on the rebuilding of our Web site. We hope to have a more user-friendly site that will provide a source of information for all who go there. Also, we will be on Facebook. (Don't ask me to explain what that means, because I have no idea! I am not into all of the "social networking" things that are so popular. I don't have a Facebook account and I don't text message; I don't even have a cell phone! I know, I am a troglodyte!) Fortunately, we have several Directors who are very savvy about all of the electronic and cyber ways of communication. They are working diligently to see that USACFA is moving into the 21st century with gusto. Hooray for youth!

"Any time that someone comments on how much he or she appreciates *CF Roundtable,* I realize all over again how much I get out of volunteering on this newsletter."

I think back to when we started USACFA. We began with a $300 loan from one of the founders. We were able to repay her within the first few months of operation. We were given a grant to buy a computer, an early Macintosh, for the Editor. Since I was the Treasurer, I did the books and I did them by hand, in a large ledger, using the double-entry system, until we received a grant and purchased a computer for me. I remember how happy I was to enter the first three-and-a-half years of records into that computer. I think it took only a few days to do it, but it surely seemed like a huge accomplishment. That computer continued to work for USACFA for the next 12 or so years. What a good investment it was.

Now, all of the Directors use computers. We all communicate by e-mail or we talk with each other by phone or Skype. (I am sure that many of the Directors text or IM each other, too.) We are able to do the business of USACFA without ever having to leave our homes. Even though we are all over the country, we can be together on conference calls and get a lot accomplished. We didn't even dream of some of these things, when we started.

So it seems that our dream of having a nice newsletter that would feel like "getting a phone call from a friend" has been more than realized. The newsletter has grown from 12 pages to as many as 44 pages, although we try to keep it at no more than 40 pages because of postage costs. We have color photographs in the middle and color highlights throughout the publication. We have received submissions from all over the USA and from several other countries. We are read in all 50 states and the District of Columbia, as well as in several other countries. Also, information has been reprinted (with permission) in many other publications.

I am sure you can see why thinking about the past 20 years with USACFA is a great way for me to get to sleep. To sleep, perchance to dream about all that has occurred and all that is to come. ▲

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

Number 6

Meet Your CF Care Team Half Way

By the time a person reaches adulthood he or she should understand that some people get along with some people better than with other people. When I speak to people on the CF Legal Information Hotline I am interested to learn of their opinions of their CF physician. Sometimes people tell me how much they love their CF physician. Other times callers will tell me that their CF physician is the worst physician who has ever walked the planet. Half of the time the two callers are talking about the same physician. Most states have only one or two CF Care Centers. The New York Tri-State area, Northern California and Ohio are the exceptions. People living in those areas of the country have between three and six CF Adult Care Center choices within a two-hour-drive radius. In the rest of the country, an adult with CF will be lucky to have access to one CF Adult Care Center within a two-hour-drive of their home.

Many adults with CF are not able to drive long distances to see a physician due to either finances or ill health. Therefore, if a person does not "click" with a CF physician or has a disagreement with the CF team, the person will have no other option than to figure out a way to make the relationship work. A small number of adults with CF are seen by adult pulmonologists not affiliated with a CF Care Center. It is often difficult to find a pulmonologist not affiliated with a CF Care Center who will treat a person with CF, due to the complex nature of the disease. Physicians do not have to treat all patients who knock at their doors. The only exception is under a law known as EMTALA. EMTALA is a federal law that requires an emergency room to treat a patient who is in an emergency situation. Sometimes an adult with CF may have to deal with physicians and nurses that are not their ideal healthcare professionals. However, before a person burns a bridge he should make sure there is another physician on the other side of the bridge who will treat him. Once you "fire" your physician there is no law that requires the physician to take you back at a later date.

Number 5

No One is Perfect

People make mistakes. Sometimes people make mistakes more than once. No one wants a healthcare professional to make a mistake that will affect health outcomes. However, CF is a complex disease. Sometimes there are no clear answers to a patient's questions. Sometimes a CF physician may have to try more than one treatment before finding a treatment that is successful. When certain treatment options do not work, discuss your concerns with a member of the CF team. Make sure you ask questions when you are unclear about your treatment options. Make an effort to understand your disease and be a partner in your care.

Number 4

Get Angry at CF

A person stops being compulsive about doing treatments and airway clearance and does not get enough rest. The person gets sick and is angry. This has happened to all of us at some point in our lives. The important thing is to not displace the anger onto the CF care team. Deal with the anger and figure out ways to make things better. Getting angry at the CF Center is a waste of energy. Energy should be used to try to get back to better health and a better treatment regimen.

Another scenario - a person does everything she is supposed to do and still gets sick. This happened to me this past summer. I was being my compliant self and still ended up sick. The cause was related to serious sinus issues I had underestimated. I was very angry at myself and at CF. When my CF care team suggested treatment with an antibiotic to which I was allergic, I was angry at them. Looking back I realize this was silly. My CF Care Center treats almost 200 patients and sometimes they may not remember everything about every patient at any given moment. I realized I needed to be angry at CF not my CF Care team. CF had caused my health to decline, not my CF Care team. I got along much better with my CF team, when I expressed my anger toward the offending party – CF. I realized it was better to use my energy to take care of myself and not waste it on being angry at my CF team.

Number 3

Take Responsibility for Yourself

Adults with CF who abuse drugs or alcohol or decide to stop doing any CF-related medical treatments eventually end up very sick. The CF physician must then spend a large portion of his time treating those patients. I hope anyone reading this article who has a family member abusing drugs or alcohol will be able to get them to seek treatment soon. Illegal drugs and the abuse of alcohol do not mix well with CF. Those people with CF who are not utilizing the medication and treatment now available to them should stop taking more than their fair share of their CF physician's time and start taking care of themselves. Excuses can go only so far. I always am humbled when I speak to a person with CF who has no family support and little income but who manages to take good care of himself and find ways to help others. Take responsibility for yourself and utilize all health care options available.

Number 2

Say Thank You

Make sure you thank your CF care team when you see them during an office visit. Thank the nurse, the respiratory therapist, the social worker and the physician. Even if the CF team member has told you something you did not want to hear, telling them

thank you is important. People are much more willing to help those who appreciate the effort they are making on their behalf. Keep this in mind.

Number 1

Look on the Bright Side

In the last issue there was an article about former USACFA Board member Pammie Post, who passed away in September 2010. Pammie devoted hundreds of hours to USACFA and *CF Roundtable*, almost from its inception. Even when she left the Board, to give someone else a chance to serve, she spent time collecting cartoons and getting the authorization needed before the cartoons could be published. Pammie shared her magnificent photographs with readers over the past few years.

I am extremely fortunate to be able to say Pammie was a dear friend of mine. Pammie never had a bad thing to say about anyone, EVER. At her memorial service her brother pointed out how incredible it was to know a person who always found the good in everyone she met. A few years after a life saving lung transplant, Pammie was diagnosed with stage-4 colon cancer. The cancer was advanced and it was unclear if she would survive. On the first day she received treatment, she sent an e-mail explaining how nice everyone at the chemotherapy center was and how lucky she was to have a chair that faced a window with the view of a beautiful tree. Pammie beat the colon cancer.

I am not saying that a positive outlook can cure cancer, but I think it certainly can help overall feelings of well being and play a part in health outcomes. Pammie was an optimist, but she also acknowledged when things were difficult or when people made mistakes. We all can learn a lot from Pammie. Some days living with CF can be hard. Trying to find a silver lining when experiencing a health setback or difficult interaction with a healthcare provider usually can make a difficult situation better. When dealing with our CF Care Center team we should give people the benefit of the doubt, communicate when we're unhappy with the way things are proceeding and be partners in our care. ▲

Beth is 44 and has CF. She is a Director of USACFA and is the Secretary. Her contact information is on page 2. She is an attorney who specializes in disability claims. You may send CF-related questions of a legal nature to: bsufian@usacfa.org.

POETRY CORNER

My Poem, My life

By Nicole Matthews

Twenty-two months old,
Diagnosed with a killer,
My parents were devastated,
The prospect, a chiller.

The life expectancy only eighteen,
The age of my ending,
Now it's thirty five,
The age of a new beginning.

The breathing is fine,
The treatments are barring,
My stomach not so kind,
The pills understanding.
The depression kicks in,
The thoughts were considered,
But none ever taken.

My life is what it is;
I wouldn't change it.
I am blessed with my health,
Others would love it.

The rose is its symbol,
A symbol of love.
A symbol that is true,
Like the one of the dove.

Sixty-five roses,
Doesn't make it any easier to say,
Cystic Fibrosis,
Is what I live with each day.

Nicole is 22 and has CF. She lives in Orchard Park, NY.

FOCUS TOPIC

SLEEP OR THE LACK OF IT

Love to Sleep ... Without Interruptions

By Paul Feld

Consistently good sleep is a challenge for many people. I have been fortunate most of my life to enjoy a good night's sleep. When I have not, there always has been a pretty good explanation, and I'll discuss these here. My wife Kristi, on the other hand, struggles with sleep constantly, and if we can ever get a handle on it, both our lives will see improvement.

I have read about sleep quite a bit. It seems for most people that sleep is easiest and most rewarding when it is consistent. Consistency means that you make an effort to go to bed within the same hour every day and wake up within the same hour of every day, whether you need to or not. For me, that has been easy to do for several years now. With no children at home anymore, I can comfortably say that almost every day I am in bed between 10 and 11PM, and I wake up between 6 and 7AM. Doing the math, I usually get about 8 hours of sleep per day. Most every day, my sleep is restful, and I use the bathroom 2-3 times during that 8 hour period. Kristi claims I snore infrequently, but I do 'breath loudly' as she puts it. It is not snoring, but may be due to the stent I have in my left bronchial tube as a follow-up procedure to my transplant. It doesn't bother me, but it's an added burden to Kristi at times. I usually have no problems falling asleep within 5 minutes of my head hitting the pillow.

The two times in my life when sleep was a problem were immediately post-transplant and when I was working heavily in my career. Sleep issues are extremely post-transplant. Given the level of prednisone and other rejection medications you are on, almost every patient post-transplant cannot sleep for intervals longer than 2-3 hours. It is very common for this to last up to almost 6 months post-transplant, until your medication doses are just about at the maintenance levels. I distinctly remember not sleeping through the night until 7 months post-transplant. That's when I knew I was becoming 'normal' again. There were also points in my career when I worked 50-65 hours per week. Thankfully, they were not that frequent, but when they did happen, sleeping was a problem. I did not get to bed at my normal times, did not wake up at my normal times, and averaged 6 hours (versus 8 hours) of sleep per night. I'd go to bed with my head spinning about what I needed to do immediately when I got up, and plan my next day as I was lying there. My job was not helping me, and sleep took a vacation.

> "It seems for most people that sleep is easiest and most rewarding when it is consistent."

My wife, Kristi, has had trouble sleeping occasionally for as long as I can remember, but recently it's become a larger issue. It is now most likely a post-menopausal issue. She is very good about getting consistent sleep, which for her is about 10:15PM-5:15AM, 7 hours of sleep. Maybe 7 hours is not enough for her, but on the rare occasion she does sleep well through the night, she seems fine the next day and very well rested. Her trouble seems to be that she can't 'turn off her thoughts when she lies down. She thinks about what she needs to accomplish tomorrow, issues that need to be resolved, the most recent conversations she's had, and on and on. She can't seem to find that 'OFF' switch. She has tried Ambien with some success, although she does not want to go through life depending on that to sleep. Once she gets to sleep, she is usually OK. It's the getting to sleep that's the problem. If I am bothering her for some reason, either snoring or loud breathing or simply rolling over a lot, she sometimes moves into our spare bedroom to try to get to sleep. Again, sometimes this works and sometimes it does not. Maybe it's just who she is that her mind won't rest, sort of like being a part of her personality. In any event, if someone out there has any thoughts on this, her ears are open. She is now trying Benadryl (recommended by friends) and Black Cohosh (an herbal remedy). The jury is still out on these. We are both keeping our fingers crossed.

Pleasant dreams, everyone! ▲

Paul is 53 and has CF. He is a Director of USACFA. His contact information is on page 2.

Information from the Internet...

Compiled by Laura Tillman

This issue brings a potpourri of articles from the Internet

NEWS RELEASES

ARIKACE™ Demonstrates Sustained Benefit In Multiple Studies And Over Multiple Cycles Of Treatment Of Pseudomonas Lung Infections

Transave, Inc., reported positive clinical trial results on its lead investigational drug, ARIKACE™ (liposomal amikacin for inhalation), an antibiotic that is entering Phase III development for the treatment of chronic lung infections. The results demonstrate significant clinical benefit and complete the company's Phase II program for the treatment of lung infections due to the bacterium, Pseudomonas aeruginosa in cystic fibrosis (CF) patients. The data from the Phase II clinical program in CF patients with Pseudomonas lung infections indicate that ARIKACE, delivered at a dose of 560 mg once daily via an eFlow® Nebulizer System for 28 consecutive days, demonstrated superior clinical benefit compared to placebo as measured by significant and sustained improvement in lung function and reduction in Pseudomonas density. This benefit was sustained over multiple cycles as observed in an open-label long-term study. In addition, ARIKACE was well-tolerated with overall events reported as consistent with those expected in a population of CF patients receiving inhaled medicines. 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), neutral liposomes that enable penetration of the biofilm. ARIKACE has been granted orphan drug status in the United States by the FDA, and has received an orphan drug designation in Europe by the European Medicines Agency for the treatment of Pseudomonas infections in patients with CF.

http://tinyurl.com/238zzc6

Pharmaxis Announces Positive Combined Phase 3 Cystic Fibrosis Trial Results

Pharmaceutical company Pharmaxis announced significant results of pooled data from its two large scale six month Phase III trials of Bronchitol (inhaled mannitol) in people with cystic fibrosis. Over the 26 weeks of the two studies, patients treated with Bronchitol had an average 7.3% improvement in lung function (FEV1) compared to baseline and a highly significant improvement compared to patients in the control group. Bronchitol produced a clinically relevant reduction in exacerbations in patients completing the study, and together with recent data showed sustained benefit in lung function out beyond 18 months. Pharmaxis Ltd is developing Bronchitol for the management of chronic obstructive lung diseases including cystic fibrosis, and bronchiectasis. Bronchitol is a proprietary dry-powder mannitol, precision formulated for delivery to the lungs through an easy-to-use, pocket-size, portable inhaler. Once inhaled its five-way action on mucus helps restore normal lung clearance mechanisms.

Continued on page 25

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.

Nap On, Nap Off—The Napper

By Andrea Eisenman

I have always been a big fan of the nap. It could be 40 minutes or a major three-hour snooze. I always feel so much better after taking one. I find them restorative, invigorating, calming, and healing. I thought of napping as a reset button. After a restful doze, I was ready for anything.

As long as I can remember in my adult life, naps have been an important part of my day. Pre-transplant it was a necessity due to extreme fatigue from not getting enough oxygen. I never had any trouble sleeping at night. My head would hit the pillow and I was out. Okay, maybe I could read for about five minutes, but after that I was completely in a deep sleep. Now, over ten years post transplant, I find I still need a nap to get through most days.

Over the years, I developed into a troubled night sleeper. I could fall asleep pretty easily but I could not stay asleep. I would sleep for about four solid hours and wake up around 3 a.m. or 4 a.m. and be awake for two to three hours. When I finally did fall back to sleep, I would wake up feeling groggy and sometimes feel as though I overslept. Because my sleep at night was not optimal, I needed to nap more often and for longer periods. This cycle of napping and not sleeping at night really started to bother me. Many health care providers told me to curtail the napping. They told me I was only making it harder for myself to sleep through the night successfully. But what they didn't understand was, my body just started to shut down during the day. For me, as for most people, around 2 p.m. to 3 p.m. was when I got the most drowsy. I would start to slur my words and could not function. All I could think of was sleeping. It was really frustrating for me, especially if I had things to do. I had thought after my transplant, "I will have all the energy to do what I want when I want." But I had not realized what a toll the transplant medications would have on my system. The prednisone brings in a whole host of side effects, some are not being able to sleep plus causing diabetes and depression. Then I had to start taking blood pressure medication due to the effects of immuno-suppressants which made me have high blood pressure.

I started to read about good bedtime routines and sleep-hygiene. Yes, there are books on this stuff. The number one reason people do not sleep well at night was caffeine too close to bedtime. So, I got rid of drinking caffeinated tea after noon and switched to diet sodas without caffeine. Another tip was to not watch television too close to going to bed. It is believed to rile one up. That was a hard one to stop as I generally do inhalations before bed and usually watch TV to pass the time during them. Another tip was, do not spend any time in your bed except for sleeping and sex. The bed, it is said, should just be for sleeping—no lounging, reading, writing, etc. I did all of these things and tried not to nap unless I absolutely had to. Then I read that depressed people have that sleeping pattern I described above. One falls asleep but does not stay asleep, tosses and turns for several hours and then, if lucky enough to fall back to sleep, wakes up feeling exhausted.

> "Because my sleep at night was not optimal, I needed to nap more often and for longer periods."

I finally went to see the psychiatrist at my transplant center. I explained my symptoms and I was given an antidepressant to try called Remeron (generic is called mirtazipine). I was warned that with this medication, I could put on a few pounds. I was told that this medication is very old and was given to patients in hospitals to get them to sleep. It also had the added benefit of curing some people's depression. At the time I first tried this medication, I was still skinny enough not to care about that side effect. The drug worked. I was able to sleep through the night and did not need so many naps. And when I did nap, I was still able to sleep through the night. My appetite also increased a bit but no real weight gain of more than five pounds. I felt great.

Since using mirtazipine, I have tried a few other antidepressants over the years. They worked on my depression but not my sleep; some even caused dehydration. So currently, I am on mirtazipine again. The only drawbacks now are the weight gain and near constant hunger. I have come to realize that I just need a lot of sleep, about eight hours at night and about a 2-hour nap daily. Mirtazipine allows me a good night's sleep plus a nap. It is a win-win for now. ▲

Andrea is 46 and has CF. She is a Director of USACFA and the Executive Editor/Webmaster. Her contact information is on page 2.

PHOTO BY STEPHEN BOYER

Fight

Was the last thing that I ever said to her.
Oh my God I was terribly mistaken.
When she said that she wanted to go home,
I thought she meant Heaven.
It didn't occur to me
That she wanted to go to our home,
Find a career, get married, raise a family
And live happily ever after.
The things that every twenty-seven year old
girl dreams of.

Fight
Was the last thing that I ever said to her.
She fought longer than three, three-minute
rounds
She fought twenty-four hours a day
Three hundred sixty five days a year
Her prize meant more to her than a title
A ranking
Or a medal
Her prize was one extra day of her life.

Fight
Was the last thing that I ever said to her.
Then she closed her eyes and she died.

Rob Rohde, 2006

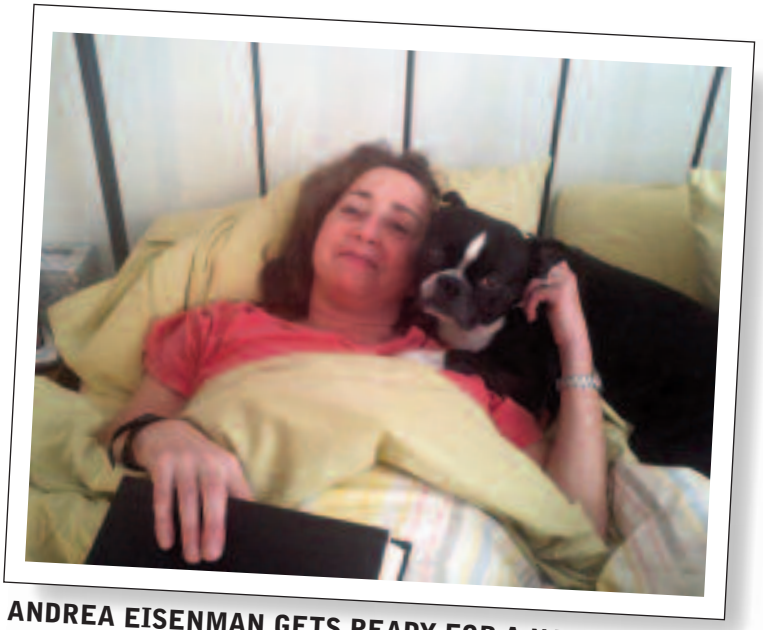
"Through the Looking Glass: Images of Adults with Cystic Fibrosis" and "Caregiver Stories" are projects of Breathing Room, a non-profit organization. Breathing Room hosts these and other projects to facilitate open and candid communication in the CF community, supports the development of a community 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...

PAUL FELD

LAURA AND LEW TILLMAN ENJOYING THE CALIFORNIA SUNSHINE.



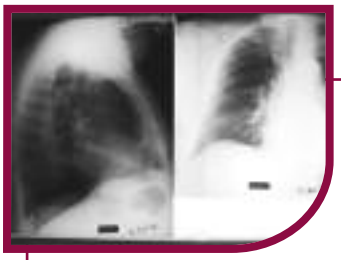
ANDREA EISENMAN GETS READY FOR A NAP WITH HER DOG, ERNIE.

JASON EGBERT

DEBBIE AND LOUIE AJINI AT VAN HOOSEN FARMS IN ROCHESTER, MI.

PETE AND JEN EISENMANN AT HER 40TH BIRTHDAY PARTY CELEBRATION, JANUARY 1, 2011! FOR FLAIR, JEN IS WEARING A DOLLAR STORE TIARA.

THE HANLEYS POSE FOR THE HOLIDAYS, TOP: JOHN (HUSBAND), KEVIN (SON) AND JEANIE. BOTTOM: DAUGHTERS JESSICA (LEFT) AND MARIA.



A DEEP BREATH IN

Who Needs Sleep? I Do!

By Debbie Ajini

Like many people with CF, I like to sleep. And like many people with CF we have issues that tend to make sleeping a challenge. I know that getting good sleep on a regular basis is key to fighting infections and staying healthy. In the past decade, as a result of various circumstances, I have been able to reduce many of the issues that were disturbing my sleep and also implement good habits that gave me a better quality of sleep. Here is what I have learned helps me sleep better.

Temperature and Air Movement

It is easier for me to breathe when my bedroom is cool at night and has some air moving either through a humidifier or fan or both. I like to use a few blankets and be chilly which helps my breathing feel easier.

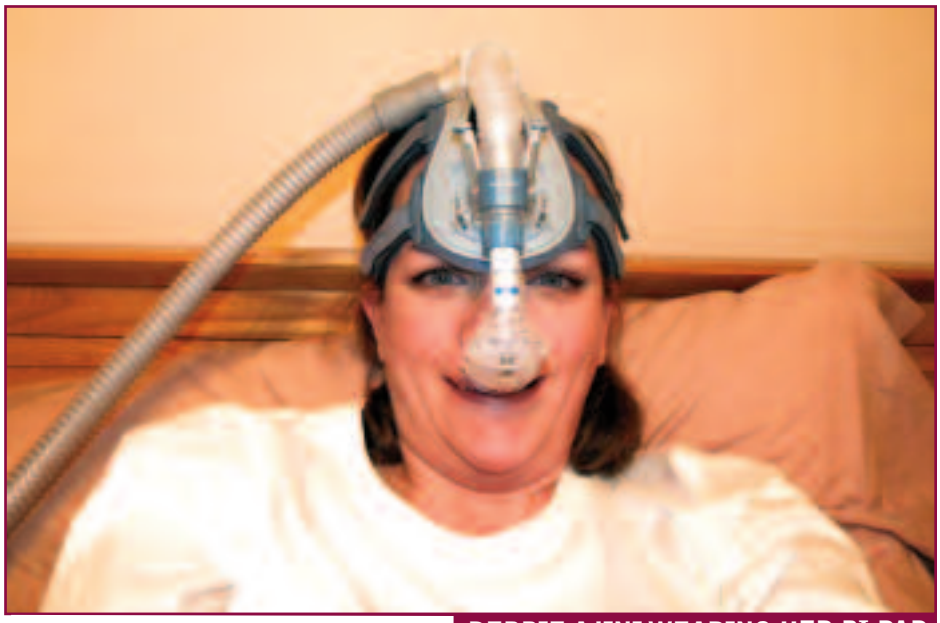
Sinus rinses

I have some sinus involvement with my CF, so I flush my sinuses every night before bed. I use a quart of warm water (preferably distilled), a tablespoon of kosher salt and a half-tablespoon of baking soda. Once that is mixed I use a 10cc syringe WITHOUT a needle to draw up some solution then squirt it into each nostril letting it run back out. This rinses my nose and sinuses of quite a bit of junk, including all the germs I have inhaled throughout the day. I truly believe this practice has helped keep me from having the average cold or sinus infection for more then five years now.

Gargling

If you take nothing else away from this article, PAY ATTENTION to this...this is life-changing! Well, only if you still have your tonsils. For years and years I had this dry, hacking cough that would wake me up throughout the night. I always chalked it up to CF and just lived with it. I finally realized I had what were called "canyons" or pockets in my tonsils (be careful if you Google this!) and food was getting stuck in there. (This is also known as tonsil stones) Once they were "stuffed" it would make me cough, especially when lying down or sleeping. And because it was related only to my tonsils the cough wasn't productive. For as long as I can remember, I have coughed up these small off-white bits of something. I never knew what they were. Again, I blamed CF and just dealt with it. Once I learned about my tonsil issue I figured out those were bits of food (and other icky stuff) that had been in those pockets. GROSS!

Then I began to realize that there were foods that seemed to irritate it. For me any dry bread is bad. Popcorn, chips and bagels are some of the worst. Now, before you get too worried...I still eat all of those things; I just have found a way to deal with them. When I do my sinus rinses, I also gargle 2-3 times with the mixture. If I have eaten a lot of problematic foods that day I will even take my syringe, fill it with my solution and directly squirt my tonsils and hope to dislodge the stuff in there. Other people I know use a WaterPik. Try not to pick at your tonsils with toothpicks, Q-tips or other items though. You do not want to harm them!



DEBBIE AJINI WEARING HER BI-PAP.

Since adding this to my regimen I have not lost more than a few nights' sleep to a plain dry cough and usually it was my own fault for eating a lot of the wrong foods and not gargling. I don't let more than two nights go by without doing it now.

BiPAP

I realize this next part will not apply to most people but for those who

can, if your FEV is getting lower or you are just having a long streak of infections, you should consider using the BiPAP machine. "BiPAP stands for Bi-level Positive Airway Pressure. It is a breathing apparatus that helps people get more air into their lungs."(From www.wisegeek.com) Many people assume this is only for end-stage CF and is just one step away from the vent. This is not true in my case. My doctor started me on it in September 2007, as a therapeutic treatment. The thinking was it could help open up some of my smaller airways and maybe get some old infected mucus out. It would also help my lungs not work as hard at breathing while sleeping, so I would get better rest. It did both of these things very successfully. I love my Bi-PAP so much it has a nickname, "The Snoot". As you can see in the picture, it kind of looks like an elephant or an ant eater! Those who know me well know how much I love my snoot and my "Snoot Snoozes".

A very important issue with both the Bi-PAP and the humidifier is cleaning. Both have standing water which we know bacteria just love. So I try to be pretty vigilant about cleaning both often and changing parts as needed.

No caffeine after 7pm

As I get older it is impossible to deny the effect caffeine has on my sleep. I have learned to avoid caffeine after 7 p.m. so I am not lying awake at 2 a.m. looking at the ceiling.

> *"[The Bi-PAP] would also help my lungs not work as hard at breathing while sleeping, so I would get better rest. It did both of these things very successfully."*

Earplugs

The snoot offers lots of white noise as does the humidifier and I thought I could never sleep with it quiet, but in the past 6 months I have been using earplugs. I sleep even better than before! The earplugs allow for a low hum of the white noise to come through but, mostly, I hear myself breathing. I can hear my husband if he speaks in his normal voice but not if he snores! I have noticed the earplugs make the most difference when I am in the hospital or a new place with noises I am not familiar with.

My health is more challenging than it has ever been, but I continue to get the best sleep of my life by following these guidelines. It does reqiure me to pack quite a bit more for overnight trips, but it is totally worth it!

I think this may be the longest column I have ever written; I guess that tells you how seriously I take my sleep and how much value I put on getting a good night's rest. I hope at least one of the steps in my routine can help bring you better sleep. Better sleep can only help us feel better and continue to fight infections. Sweet dreams! ▲

Debbie is 40 and has CF. She is a Director of USACFA. Her contact information is on page 2.

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

Valerie Vandervort
Claremore, OK
39 on January 8, 2011

Andrea Eisenman
New York, NY
46 on November 28, 2010

Transplant

Paul Feld
Florissant, MO
Bilateral lung
6 years on October 23, 2010

WELLNESS

The Key Ingredient for Living Well With CF

By Julie Desch, MD

It's been an interesting fall for me, and before that, an interesting spring and summer. Losses of my mother, a beloved dog, and a home of seven years, combined with acquisition of MRSA and its associated pariah status in the CF world to leave me reeling. Not surprisingly, the stress of all of the above led to two of what seemed like endless rounds of IV antibiotics for exacerbations of my CF, culminating most recently with bilateral pneumonia and a stint in the Big House. Then came yet another allergic reaction to an antibiotic, as my immune system continues to make treatment of lung infections akin to an internal medicine jigsaw puzzle. I won't go into the resultant emotional turmoil, only to say that I have been challenged.

To paraphrase the First Noble Truth of Buddhism: life is hard. I am still on the lookout for the swarms of locusts.

I have no illusions about this. I know that many of you have gone through similar, if not worse, periods of your life. After all, I just turned fifty years old! Twelve point six years later than that fateful number, I am alive and kicking hard, despite two copies of dF508. At some point, I knew I would be faced with real, big-time problems from CF. It seems that the time is now.

So, this article deals with an issue that is dear to my heart right now, and I suspect that you might relate. I got knocked down — hard — and it's time to get up again. But, how?

Resiliency: The Bounce Factor

What is it that makes some people able to "bounce back" after a seemingly horrible tragedy, when others fall completely apart after a relatively minor setback? For some, loss or illness sparks an inner strength that provides motivation to take incredibly positive action. Lance Armstrong comes to mind, as do the Stenzel twins, and so many other Heroes of Hope who we read about. My brother, Tom, who somehow managed to come back time after time from CF-related health problems, his FEV_1 in the *teens* for ten years, was another great example of the power of this "factor."

> *"For some, loss or illness sparks an inner strength that provides motivation to take incredibly positive action."*

JULIE DESCH, MD

Fortunately, many very smart people are now doing research that looks at this very question and are coming up with remarkable findings. "Resilience" is the subject of such studies. This work is part of the broader category of "positive psychology". Whereas the majority of past research in psychology has dealt with what is wrong with people and how best to identify and treat mental illness, the newer field of positive psychology studies what makes people flourish. Barbara Fredrickson, PhD, a world-renowned expert in positive psychology, has written a fascinating book entitled *Positivity*, in which she describes a finding that some compare to the "discovery of gravity" in the mental health arena. I highly recommend reading this book. It is extremely well written, easy to understand, and well worth the time and money.

To greatly oversimplify her discovery, Fredrickson and colleagues discovered a tipping point positivity ratio of 3:1—three positive emotions to one negative emotion. Above this tipping point people are better able to bounce back after adversity. They are *resilient*. They also happen to be healthier, and have more resources available to change and grow. Fredrickson describes an "upward spiral" that allows people above this tipping point to flourish in a life that is often hard. Below this tipping point, people languish and fall into a downward spiral. As the ratio dips below 1:1, depression occurs. Here's the scary statistic: Eighty percent of people who take a

positivity self test (found at www.positivityratio.com) score below the 3:1 tipping point ratio. They are languishing, at best, and are not equipped to bounce back from life's hard knocks. Those of us with cystic fibrosis cannot afford to be in this group!

The Heart of Human Resilience

My favorite line from Positivity, is the following: "*Positivity* we've discovered, is at the heart of human resilience." I don't have the space to go into how this discovery was made, or the abundant follow-up studies that confirm it. What is important to understand is that you absolutely have the ability to increase your positivity ratio and, thereby, increase your own resilience.

There are, of course, two ways to increase a ratio. You can increase the numerator or decrease the denominator. The interesting finding is that resilient people are not Polyannas; they do not bury their heads in the sand and refuse to admit that life is hard. Indeed, they experience the same negative emotion that we all experience during and after hardship. This is good news for us, and it is why I think adults with CF would be an interesting resiliency study group. As you know, despite doing everything you can to ward off illness – never missing an aerosol, regularly doing airway clearance with a vengeance, never missing a day of exercise, eating right and maintaining a healthy weight, getting enough sleep, taking all of the requisite pills and supplemental vitamins, and actively reducing and managing stress – despite *all of this*, we still get sick...sometimes we get extremely sick. I can attest that this is frustrating and can lead to the very negative emotions of anger, grief, and fear. It isn't necessary to deny these feelings to positively affect the ratio in question. The most resilient of Fredrickson's and others' studies had all of the normal negative emotions that accompany adversity. The difference was in their emotional flexibility.

Resilient people are capable of being open to moments of positivity, even amidst great suffering. They can find joy, love and gratitude by connecting with others. They can find a way to feel awed by nature and inspired by others who thrive within imperfect bodies. They can nourish grains of hope for the future by setting goals that push them just the right amount in just the right way. They can savor the generosity of others who truly care and want to help. All of these things can increase the positivity ratio without denying the reality and the general suckiness (is that a word?) of normal negative emotions that accompany an illness or loss.

Building Positivity

Fredrickson describes twelve "tools" for building positivity. I highly recommend reading the book for information about all twelve, but I'll describe two that have kept me afloat for the last nine months:

1) Meditation. You knew I was going to say this, didn't you? But, it's not just me...studies show that mindfulness and loving-kindness meditation reduce anxiety and depression, and assist in coping with chronic illness. Mindfulness generates openness, while loving-kindness meditation develops capacity for kindness – for yourself (and your ailing body) as well as for others. Two of the "tools" to generate positivity are 1) be open, and 2) cultivate kindness. Two birds. One stone.

During my most recent nine-month confirmation of the First Noble Truth (described above), my meditation practice was the one constant I could count on, and it kept me grounded. Thirty minutes a day of "just sitting there" was my investment. In return, I had a sense—sometimes only fleeting, but it was there—that I was basically ok, and would get through whatever happened. Thirty minutes is not necessary. I know how precious time is when it seems like most of your waking day is spent on treatments. Ten minutes a day is a great start. I will not go into instructions on how to do these forms of meditation here, but there are excellent descriptions of each online, as well as numerous books on this subject.

2) Developing Distraction: It is amazingly easy to be swept away in the downward spiral of negative thinking and the resulting negative emotions. One positivity-building tool is to learn to dispute negative thinking...to simply argue with yourself, and point out the various ways the situation is not as dire as you imagine.

This is great when it works, but there are times when, try as you might, arguing with yourself is futile. This is the time for distraction! When you are on a downward spiraling thought/emotion track and can't seem to slow yourself down, you find a way to jump onto an entirely new track.

Example: My recent passion in the fitness arena is kettlebell training. I've been doing this for almost two years, and have become quite a fanatic. In fact, prior to getting sick, I had worked up to being able to lift one-third of my body weight over my head with one arm...three times in a row, before switching to the other side and repeating. This may not sound like much, but it impressed my kettlebell trainer to the point that he kept telling me that I should become an RKC—Russian Kettlebell Certified trainer. Attending and passing the RKC workshop is to kettlebell training what running a marathon is to a

Continued on page 27

The Insurance Dilemma

By Mike Hale

I decided to write this little bio to explain some of the insurance hoops and what some of us have to go through. In a way, I think I'm doing this to help with my own stress as I feel the world is weighing down on me and, at times, I'm not sure what I am going to do.

I currently am a federal employee for the Air Force. I work as a systems administrator, which is a fancy way of saying computer nerd. I take care of the high end special server computers and storage equipment where data is stored, along with all the other duties that go along with that. This is a 40 hour-a-week job. Rarely do I have to work extra; only if there is some special maintenance or if a problem comes up. I truly love what I do and like where I work.

I live in the Dayton, Ohio area, very close to Wright Patterson AFB, which is also my place of employment. I was born in Dayton. I was born with both cystic fibrosis and an uncorrectable vision impairment. My mother did very well taking care of me with little or no resources. I spent my young life receiving disability, due to my vision impairment. I believe it was easier to get SSI benefits for my vision rather than for CF, because with vision you just have to have vision under a written amount whereas with CF there is more of a gray line; but I'm not sure. However, SSI is what helped pay the bills along with whatever job my mom could get. I know she went without food at times to make sure I was taken care of. She pushed me to go to college so I could have a better life and tried to make sure I didn't make some of the same mistakes she did when she was young.

Let's fast forward now to my first job; my biggest concern when I got my first job was the cost of my medical expenses and what would happen with Medicaid. My first job was with a small company and I was offered $27,000 a year. This was a lot of money to me, coming from living on disability, food stamps and a small amount of income that Mom made. I took the job and reported to Medicaid about this income. Well, the first thing Medicaid wanted to do was give me a "spend down" which was most of my income. Luckily I found a loophole in the system that kept them from doing this.

> "If it was not for my vision impairment, I probably would not have received as much help as I have received from the state and federal governments."

Since Social Security found me disabled due to being legally blind and I fell under a certain income, they said I qualified for 1619B. This is a program where you can work and be disabled but you're exempt from a spend down. I immediately got a letter from Social Security that stated I fell into this category and provided it to Medicaid. My spend down was gone. What I didn't mention is I did elect to take the insurance from the company I was working for but, like most insurances, it doesn't cover some of the more expensive drugs or procedures very well.

This worked for many years; I was laid off a couple of times and took short term contract positions in the early 2000s but did not have a new steady job until 2003. In 2003, I accepted a contracted position with Wright Patterson AFB. It was as a computer tech. Luckily my salary was higher but still under that level that qualified me for 1619B. I was making about $36,000 a year starting out. I again paid for company insurance to help cover costs so everything would not fall on Medicaid.

Around 2007 Social Security reviewed my case and decided I was eligible to receive Medicare. I will state for the record now, Medicare is horrible to try to deal with. A lot of companies will not deal with Medicare recipients and getting them to cover anything was a fight. So here is the order of how things work. My insurances would process claims in this order: 1) Work insurance, 2) Medicare and 3) Medicaid.

In 2008 I was promoted to doing the work I do now and I was still a contractor. My pay went up, since this position requires more skill, work and responsibility. All this time I'm sending paystubs to social security. When they receive a paystub, they are supposed to subtract what are called "blind expenses". This is a fancy way of saying your net income instead of your gross. I found out about 6 months ago they were not processing these pay stubs correctly so I had to resend about two years

worth of paystubs. Luckily, I had most of them. After reprocessing them, they decided that I'm making too much for 1619B, which meant I would have a spend down.

I did not mention, around April I was hired to do the same job as a government employee. I sit in the same seat and do what I did before; it's just that my paycheck comes from a different spot. I have also taken one of the higher cost insurance benefits and am also paying for FSA, which is a flexible spending account. This allows a given amount to be taken out of your paycheck pre-tax and you are reimbursed from that amount for out-of-pocket medical costs.

Now the fun part, I mentioned that there would be a spend down. This seemed to cause a domino effect. So I will discuss one insurance at a time and the effects this has had to help with eliminating confusion, because this is very confusing especially if you aren't familiar with all the rules.

Medicaid told me my spend down would be $1800+ a month. I guess I'm not supposed to eat or something. Well, luckily the Medicaid rep did some research and discovered "Medicaid for Disabled But Working". This had a premium cost of $306. So she went ahead and signed me up for this.

Here is where some of the domino effect comes in. Medicare changed, based on the change in Medicaid. I did have Medicare A, B and D. Now Medicare wants a premium of $440 for parts A and B, but I have heard nothing on part D yet. So I talked to Medicaid and they told me as long as I'm eligible for Medicare, they do not cover prescriptions. My eligibility runs out in the second quarter of 2011 for Medicare. Then they will cover my prescription costs, but I think my premium will go up.

I have checked with the insurance that I have from work and it leaves 30% of the cost of drugs like TOBI, Pulmozyme and Cayston for me to cover. I can't afford this nor all the premiums. There is a program in my state called BCMH which helps CF patients with some things, but their budget had been cut a lot so I'm not expecting much from them.

After all this, here is my complaint. If it was not for my vision impairment, I probably would not have received as much help as I have received from the state and federal governments. Not only this, but the information about 1619B was never volunteered info; I had to do a lot of research to find out about it. The system is not made for people like me who want to work but still need help with drug and other costs. For those who thought the government insurance plans were top notch if you were a federal employee, don't be fooled. The system would prefer me to sit home and get free Medical, SSDI payments and food stamps rather than help cover Medical costs. No wonder so many people end up living on social security and not working. Some people would tell me to quit working; in fact one person has. I tell them and everyone else that I refuse to. Not only do I love what I do and would be bored and unhappy not working, but this is the only way my wife will receive benefits in the event of my death.

My plan as of now is to just live without certain drugs until Medicare is gone and then, hopefully things will go back to normal. ▲

Mike is 35 and has CF. He lives in Beavercreek, Ohio.

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POETRY CORNER

By Jennifer Mackey

I have been receiving *CF Roundtable* for several years now, off and on. I read it both before and after my double lung transplant (09/25/10 - USC University hospital) and have found it to be informative and applicable to the lives of patients, both pre- and post-transplant.

As I was looking through *CF Roundtable* for the address to send my renewal form and check, I came across the invitation for CF patients to send their creative work into the magazine.

My sisters and brothers and I grew up in abusive homes. In order to get away from that and have my transplant in relative peace, I moved to California and ceased communication with all family members, except my sister who is a year-and-a-half younger than I. She has been and remains so supportive, despite the obvious difficulties and responsibilities her life has handed her.

Naturally the lessons I learned in childhood carried over well into adulthood, and I kept "finding" myself in abusive relationships. I have done my best to stay focused on being independent and remaining healthy. In fact, I've worked most of my life. Several years ago, I took the Metro rail to/from my work at an animal hospital and this factors into my poem.

I feel so bad for people who feel hurt and alone. I know that feeling lonely can contribute to staying in a bad relationship, and I know that being hurt contributes to feeling lonely. The CF patient who feels cut-off from others due to their "differences" may tolerate abuse, in exchange for companionship and financial support.

Occasionally, I've come across people who have divulged that their relationships are causing them pain. I have listened to them and then quickly put them in contact with social services in their area that may be able to help. If you decide to print my poem, and if you think this e-mail may help somebody, then I'm absolutely okay with both being printed in your newsletter. I'm afraid the poem is more "free association" than art, but it may still resonate with CF patients who are having a difficult time with relationships.

Jennifer is 36 and has CF. She lives in Harbor City, CA. She would be thrilled to e-mail with any CF adult or parent of a child with CF, especially anybody considering or facing lung transplant. Her e-mail is: jenniferjmackey@yahoo.com

Your Nothing

Ask me why
and I'll tell you how
I came to reside
in this place you call Hell

The place is designed
engineered for me
I understand the sound of loneliness
of Hereafter, and just me

Have you ever heard
the sound of lonely?
The wires high-strung
and the rails screeching stop?

I remember
the doors flung wide
brave, sincere and solitary
stepping inside

I always took a stand
the small, the weak, the hurt
supposed weakness in vain compassion
open to your poison

And how you followed through!
In streams, rivulets, tears
sensing courage, hiding your fear
hoping, then believing in "too late"

But I left you, pounding
then kicking at my door
I left you, your choice
to stay outside, or flee

I left you, always close
sensing what you had lost
I left you
with the nothing you always had

And how you believed
you hated me then!
thinking I abandoned you
cold as a babe, left on my doorstep

Your righteous hatred
at being left
by someone so deep in your debt
possession, control, revenge all lost

So that was me then
this is me now
compassion ground to fine powder
carried by hot wind

joy, love and laughter
for now, denied
just lonely
in this place I reside

Bronchitol has received Orphan Drug Designation and fast track status from the US Food and Drug Administration and Orphan Drug Designation from the European Medicines Agency.
http://tinyurl.com/255sdpl

One Step Closer To A Drug Treatment For Cystic Fibrosis, MU Professor Says

The *Journal of Biological Chemistry* has published findings by Tzyh-Chang Hwang, a professor in the School of Medicine's Department of Medical Pharmacology and Physiology and the Dalton Cardiovascular Research Center. Hwang's work focuses on the two most common genetic mutations among approximately 1,500 mutations found in patients with cystic fibrosis. These two mutations cause specific chloride channels in the cell, known as the Cystic Fibrosis Transmembrane conductance Regulator (CFTR) chloride channels, to malfunction. This ultimately leads to repeated pneumonia, the primary cause of most deaths associated with cystic fibrosis. The most recent study found that manipulating the sensor of the channel protein can significantly rectify the malfunction of the mutated channel, thus opening the door to a drug design that may eventually be a "real cure". The publication is titled, "Optimization of the degenerated interfacial ATP binding site improves the function of diseases related mutant cystic fibrosis transmembrane conductance regulator channels."
http://tinyurl.com/3y65y2h

Human Growth Hormone Shows Promise in Treating Cystic Fibrosis Symptoms

Human growth hormone can be used successfully to treat some symptoms of cystic fibrosis, but its impact on the disease itself remains unknown. The report, Effectiveness of Recombinant Human Growth Hormone (rhGH) in the Treatment of Patients with Cystic Fibrosis, finds that the use of human growth hormone increases height and weight, may improve lung functioning, and may strengthen the bones of patients with cystic fibrosis. Researchers found evidence suggesting that human growth hormone therapy reduces the need for hospitalizations, but could find no evidence that the therapy prolongs life or improves health-related quality of life. The use of human growth hormone was also found to raise blood sugar, which may over time lead to the development of diabetes in some patients.
http://tinyurl.com/38pz373http://tinyurl.com/26xezm5

Discovery Labs' cystic fibrosis drug gets orphan status

Biotech company Discovery Laboratories Inc said its experimental drug for the treatment of cystic fibrosis received orphan drug designation from U.S. health regulators. Last month, the company said the drug — aerosolized KL4 surfactant — was found to be safe and well-tolerated in a mid-stage trial. Surfactants are produced naturally in the lungs and are essential for breathing. Discovery Labs' KL4 surfactant technology produces a synthetic surfactant that is structurally similar to pulmonary surfactant.
http://tinyurl.com/3455v2j

Cystic fibrosis gene typo is a double whammy

An imbalance of salt and water in patients with cystic fibrosis makes their lungs clog up with sticky mucus that is prone to infection. The cause of the offending imbalance is a well-known genetic error, one that blocks the molecular expressway for tiny chloride ions to move across the surface of the lungs. Researchers have found that the gene mutated in cystic fibrosis not only controls traffic on the chloride highway, but also keeps the sodium highway from being overused. The finding suggests that the mutation affects the flow of two different ions that are important to keep the mucus on the surfaces of the airways hydrated. Clarifying this link between the genetic defect and the thick sticky mucus in cystic fibrosis lungs could help researchers develop better therapies. A number of scientists have hypothesized that CFTR also controls the movement of other ions, such as through the epithelial sodium channel or EnaC. This channel has been shown to be overactive in transporting sodium ions in the airways of cystic fibrosis patients.

Continued on page 27

New Donor Designation

Beginning this year, 2011, USACFA will acknowledge donations of $5000 or more as **Sustaining Partners.** These donors will be recognized in a special place in *CF Roundtable* for four issues after the donation. They also will be recognized on our new Web site that is under construction.

The **Benefactors** will stay the same as before, with one change; **Platinum** now will be: $1000 to $4999. We hope that all our donors realize that even $1 is an important donation to us and to our readers. We appreciate the generosity of all of our donors, benefactors and sustaining partners. Thank you.

Patient Assistance Programs and Other Resources

This list of available programs is courtesy of CFRI. They encourage you to check their Web site at: www.CFRI.org for updates. Also, they appreciate any suggestions you may have for information to add to this list.

Patient Assistance Programs

Abbott
Androgel® CREON® PROMETRIUM® Patient Assistance Program http://www.abbottpatientassistance-foundation.org
1-800-256-8918

Eurand Pharmaceutical
Zenpep Points and Assistance Programs
http://www.zenpep.com/site/cfhcp.aspx
1-888-936-7371

Genentech, Inc.
Genentech Access Solutions
http://www.genentechaccesssolutions.com/portal/site/AS/
1-866-4-ACCESS
Pulmozyme Access Solutions Co-Pay Card Program
https://www.activatethecard.com/pulmozyme/appSecWelcomeReq.jsp
1-877-794-8723

Gilead
Cayston Access Program
http://www.gilead.com/us_advancing_access
1-877-7CAYSTON

Nestle Nutrition
http://www.cfri.org/pdf/nestlePatientAssistanceForm.pdf
1-952-848-6112

Novartis Pharmaceuticals
TOBI® Co-pay Assistance Program
http://www.tobitime.com/info/tools/patientassistance.jsp
1-866-598-8624

Other Resources

Cystic Fibrosis Patient Assistance Foundation
Assistance for affording medications and devices for managing CF
http://www.cfpaf.org

Cystic Fibrosis Services
Additional patient assistance programs for those without insurance coverage
https://www.cfservicespharmacy.com/PatientAssistance/

Boomer Esiason Foundation
Links to assistance programs for Tobradex, Creon, Aceon, Estratest HS, Prometrium, EstroGel, Pulmozyme, Advair, and Cipro
http://www.esiason.org/pdf/Cystic.pdf

HospitalBillHelp.org
Guidance for Californians facing hefty hospital bills
http://www.hospitalbillhelp.org

NeedyMeds.org
Additional Patient Assistance Programs
http://www.needymeds.org

Partnership for Prescription Assistance
Database of Patient Assistance Programs
(Search by drug, company or program name)
http://www.pparx.org/prescription_assistance_programs/list_of_participating_programs

Patient Advocate Foundation
Mediation and arbitration services for patients with debilitating and life-threatening illnesses.
http://www.patientadvocate.org/

RXAssist Patient Assistance Program Center
Database of Patient Assistance Programs
(Search by drug, company or program name)
http://www.rxassist.org/patients/default.cfm

DESCH *continued from page 21*

jogger. Each week, he would try to convince me I should do it, and I would try to convince him that 1) I was too old, and 2) my lungs would never work well enough for me to pass the endurance test, and 3) I'd probably fork over the fee (not cheap) for the workshop and then be on IVs when it rolled around. Every argument I raised, he countered with a better one. He almost had me convinced.

Then I land in the hospital with bilateral pneumonia. In goes a port and I literally can't exercise because I have no ATP in my body, not to mention there was a needle in my chest for three weeks. A serious descending spiral of negativity ensued.

Normally, for fun during treatments, I will watch YouTube videos of kettlebell workouts or read books on the subject to get ideas. Weird, I know. But that wasn't happening in the hospital, nor was I in the mood to even think about my pet pastime during my convalescence. It was just too depressing.

So, what did I do instead? I decided that I really wanted to learn about quantum physics. Talk about a track change! But it worked. I stopped feeling sorry for myself, even if only for an hour or so each day. I became curious about something I have wanted to understand for years but never had time for. It held my interest, and it required no physical effort at all. Reading and learning about a new subject was completely unaffected by my health, and it dragged my mind away from my CF woes. It's literally impossible to think negative thoughts when you are trying to follow a complicated subject.

It's amazing how as little as an hour a day of stretching your mind can affect your mood. I can't say I exactly understand quantum physics (what I understand is that it isn't completely understandable). It pulled me out of my doldrums, though, and now I intersperse a physics lecture now and then between Kettlebell videos.

But don't take my word for it. Try it yourself. Maybe quantum physics won't do it for you. Perhaps it will be through music, or scrap booking, or origami, or humorous movies, or...I don't know, but you do.

In the meantime, I've signed up for the RKC in April. ▲

Julie is 50 and is a physician who has CF. You may contact her at: jdesch@usacfa.org

TILLMAN *continued from page 25*

http://tinyurl.com/289oaj5

CFRD

Managing diabetes in cystic fibrosis. Laguna, T. A.; Nathan, B. M.; Moran, A. Diabetes, Obesity and Metabolism, Volume 12, Number 10, October 2010, pp. 858-864(7)

Cystic fibrosis related diabetes (CFRD) is the most common co–morbidity in persons with cystic fibrosis (CF). As the life expectancy of persons with CF continues to increase, the need to proactively diagnose and aggressively treat CFRD and its potential complications has become more apparent. CFRD negatively impacts lung function, growth and mortality, making its diagnosis and management crucial in a population already at high risk for early mortality. Compared to type 1 and type 2 diabetes, CFRD is a unique entity. The physiology of CFRD is complex, likely consisting of a combination of insulin deficiency, insulin resistance and a genetic predisposition towards the development of diabetes. However, the hallmark of CFRD is insulin deficiency. The goals of treatment of the CFRD population are to reverse protein catabolism, maintain a healthy weight, and reduce acute and chronic diabetes complications. Creating a partnership between the treatment team and the patient is the ideal way to accomplish these goals and is essential for successful diabetes care.

http://tinyurl.com/27h7os9

BACTERIA

***Aspergillus fumigatus* colonisation in cystic fibrosis: implications for lung function?** Angélica M.M. De Vrankrijker, Cornelis K. Van Der Ent, Ferdinand Teding Van Berkhout, Rebecca K. Stellato, Rob J.L. Willems, Marc J.M. Bonten, Tom F.W. Wolfs. Clinical Microbiology and Infection. Nov 18

Aspergillus fumigatus is commonly found in the respiratory secretions of patients with cystic fibrosis (CF). Although allergic bronchopulmonary aspergillosis (ABPA) is associated with deterioration of lung function, the effects of A. fumigatus colonisation on lung function in the absence of ABPA are not clear. Although colonisation with A.fumigatus is more commonly found in patients with more severe lung disease and increased treatment burden, it is not independently associated with lower lung function or more severe lung function decline over a 5–year period.

http://tinyurl.com/2929y4o

Infection With Transmissible Strains of Pseudomonas aeruginosa and Clinical Outcomes in Adults With Cystic Fibrosis. Shawn D. Aaron, MD;,Katherine L. Vandemheen, MScN; Karam Ramotar, PhD; Tracy Giesbrecht-Lewis, BSc; Elizabeth Tullis, MD; Andreas Freitag, MD; Nigel Paterson, MD; Mary Jackson, MD; M. Diane Lougheed, MD;

Continued on page 28

Christopher Dowson, PhD; Vijay Kumar, MD; Wendy Ferris, MSc; Francis Chan, PhD; Steve Doucette, MSc; Dean Fergusson, PhD. . 2010;304(19):2145-2153

Studies from Australia and the United Kingdom have shown that some patients with cystic fibrosis are infected with common transmissible strains of Pseudomonas aeruginosa. The objective was to determine the prevalence and incidence of infection with transmissible strains of P aeruginosa and whether presence of the organism was associated with adverse clinical outcomes in Canada. A common strain of P aeruginosa (Liverpool epidemic strain/strain A) infects patients with cystic fibrosis in Canada and the United Kingdom. Infection with this strain in adult Canadian patients with cystic fibrosis was associated with a greater risk of death or lung transplantation.

http://tinyurl.com/2eenztv

TREATMENTS

Effect of VX-770 in Persons with Cystic Fibrosis and the G551D-*CFTR* Mutation

Frank J. Accurso, M.D., Steven M. Rowe, M.D., J.P. Clancy, M.D., Michael P. Boyle, M.D., Jordan M. Dunitz, M.D., Peter R. Durie, M.D., Scott D. Sagel, M.D., Douglas B. Hornick, M.D., Michael W. Konstan, M.D., Scott H. Donaldson, M.D., Richard B. Moss, M.D., Joseph M. Pilewski, M.D., Ronald C. Rubenstein, M.D., Ph.D., Ahmet Z. Uluer, D.O., Moira L. Aitken, M.D., Steven D. Freedman, M.D., Ph.D., Lynn M. Rose, Ph.D., Nicole Mayer-Hamblett, Ph.D., Qunming Dong, Ph.D., Jiuhong Zha, Ph.D., Anne J. Stone, B.A., Eric R. Olson, Ph.D., Claudia L. Ordoñez, M.D., Preston W. Campbell, M.D., Melissa A. Ashlock, M.D., and Bonnie W. Ramsey, M.D. N Engl J Med 2010; 363:1991-2003

A new approach in the treatment of cystic fibrosis involves improving the function of mutant (G551D-*CFTR*) cystic fibrosis transmembrane conductance regulator (CFTR). VX-770, a CFTR potentiator, has been shown to increase the activity of wild-type and defective cell-surface CFTR in vitro. This study to evaluate the safety and adverse-event profile of VX-770 showed that VX-770 was associated with within-subject improvements in CFTR and lung function. These findings provide support for further studies of pharmacologic potentiation of CFTR as a means to treat cystic fibrosis.

http://tinyurl.com/234yjck

Pharmacodynamics and tolerability of high-dose, prolonged infusion carbapenems in adults with cystic fibrosis A review of 3 cases. Catharine C. Bulik, Richard Quintiliani Jr., J. Samuel Pope, Joseph L. Kuti, David P. Nicolau. Respiratory Medicine CME. Volume 3, Issue 3, Pages 146-149 (2010)

Cystic fibrosis (CF) is a disease marked by repeated acute pulmonary exacerbations of infections, often caused by Pseudomonas aeruginosa and Burkholderia cepacia. As antibiotic susceptibility declines, dose optimization must be considered to provide adequate pharmacodynamic exposure. Three cases of CF exacerbations in adults caused by multi-drug resistant *P. aeruginosa and B. cepacia were* reported. Each case required dosing strategies greater than currently recognized in package inserts: meropenem 3000mg every 8h (3-hour infusion) and doripenem 2000mg every 8h (4-hour infusion). Pharmacokinetic analyses demonstrated that targeted pharmacodynamic exposures were achieved against most of the organisms, resulting in clinical improvements despite laboratory reported resistance. The high-dose, prolonged infusion regimens were well tolerated demonstrating that pharmacodynamically optimized carbapenem regimens may be used safely and effectively in patients with limited conventional treatment options.

http://tinyurl.com/377fve6

Tobramycin inhalation powder for P. aeruginosa infection in cystic fibrosis: The EVOLVE trial. Konstan MW, Mini P, Brockhaus F, Zhang J, Angyalosi G. Pediatr Pulmonol. 2010 Oct 20. [Epub ahead of print]

Tobramycin inhalation solution is used to treat chronic Pseudomonas aeruginosa lung infection in cystic fibrosis (CF) patients. The efficacy and safety of a novel, light-porous particle, dry-powder formulation of tobramycin, which was developed to improve delivery efficiency to the airways and substantially reduce the delivery time, was evaluated. In this randomized, double-blind study, patients with CF (age 6-21 years) received tobramycin inhalation powder (112 mg tobramycin) twice daily (n = 46) or placebo (n = 49) via the T-326 Inhaler for one cycle, followed by two open-label cycles (all patients). Cycles were 28 days on, 28 days off treatment. The primary endpoint was change in forced expiratory volume in 1 sec (FEV(1)) % predicted from baseline to Day 28 of Cycle 1. The study was terminated early based on positive results in the interim analysis. Tobramycin inhalation powder significantly improved FEV(1) % predicted versus placebo at Day 28. Similar changes in FEV(1) were seen in patients switching from placebo to tobramycin inhalation powder in Cycle 2; improvements were maintained over time. Tobramycin inhalation powder also reduced sputum P. aeruginosa density, respiratory-related hospitalization and antipseudomonal antibiotic use versus placebo. The most common adverse event was cough; the frequency of cough was higher in patients receiving placebo

versus tobramycin inhalation powder in Cycle 1. Tobramycin inhalation powder was not associated with ototoxicity or nephrotoxicity. Administration time was between 4 and 6 min. In conclusion, tobramycin inhalation powder was effective and well tolerated in CF patients, and may offer an important treatment option to decrease the treatment burden of CF pseudomonas lung infections.
http://tinyurl.com/29zbmu9

Sodium Nitrite-Mediated Killing of the Major Cystic Fibrosis Pathogens Pseudomonas aeruginosa, Staphylococcus aureus, and Burkholderia cepacia under Anaerobic Planktonic and Biofilm Conditions. Tiffany A. Major, Warunya Panmanee, Joel E. Mortensen, Larry D. Gray, Niel Hoglen, and Daniel J. Hassett. Antimicrobial Agents and Chemotherapy. November 2010, p. 4671-4677, Vol. 54, No. 11

A hallmark of airways in patients with cystic fibrosis (CF) is highly refractory, chronic infections by several opportunistic bacterial pathogens. A recent study demonstrated that acidified sodium nitrite (A–NO2–) killed the highly refractory mucoid form of Pseudomonas aeruginosa, a pathogen that significantly compromises lung function in CF patients. Thus, in summary, the authors demonstrate that A–NO2– is very effective at killing these important CF pathogens and could be effective in other infectious settings, particularly under anaerobic conditions where bacterial defenses against the reduction product of A–NO2–, nitric oxide (NO), are dramatically reduced.
http://tinyurl.com/38rs649

FYI

Cystic fibrosis-associated liver disease. Ulrike Herrmann, Gerd Dockter, Frank Lammert.

Best Practice & Research Clinical Gastroenterology. Volume 24, Issue 5, Pages 585-592 (October 2010)

Liver disease is increasingly common in cystic fibrosis (CF). As new therapeutic options emerge, life expectancy increases and common hepatobiliary manifestations impact on quality of life and survival of CF patients. Hepatobiliary abnormalities in CF vary in nature and range from defects attributable to the underlying *CFTR* gene defect to those related to systemic disease and malnutrition. Today complications of liver disease represent the third most frequent cause of disease-related death in patients with CF. The authors review molecular and clinical genetics of Cystic fibrosis, including genetic modifiers of Cystic fibrosis–associated liver disease, and provide practical recommendations for genetic testing, diagnosis and treatment of hepatobiliary manifestations in Cystic fibrosis.
http://tinyurl.com/29n9qd3

Computed tomography and magnetic resonance imaging in cystic fibrosis lung disease. Monika Eichinger MD, Claus-Peter Heussel, Hans-Ulrich Kauczor, Harm Tiddens MD, PhD, Michael Puderbach MD. Journal of Magnetic Resonance Imaging. 2010;32:1370–1378

Computed tomography (CT) is the current "gold standard" for assessment of lung morphology and is so far the most reliable imaging modality for monitoring cystic fibrosis (CF) lung disease. CT has a much higher radiation exposure than chest x–ray. The cumulative radiation dose for life–long repeated CT scans has limited its use for CF patients as their life expectancy increases. No dose would be preferable over low dose when the same or more relevant information can be obtained. Magnetic resonance imaging (MRI) is comparable to CT with regard to the detection of most morphological changes in the CF lung. It is thought to be less sensitive to detect small airway disease. At the same time, MRI is superior to CT when it comes to the assessment of functional changes such as altered pulmonary perfusion.
http://tinyurl.com/39jffnn

Pulmonary exacerbations are associated with subsequent FEV1 decline in both adults and children with cystic fibrosis. Don B. Sanders MD, MS, Rachel CL. Bittner MS, Margaret Rosenfeld MD, MPH, Gregory J. Redding MD, Christopher H. Goss MD, MS. Pulmonology. Article first published online: 21 OCT 2010

There is a strong association between the frequency of pulmonary exacerbations and subsequent decline in pulmonary function. In adults, having 3+ exacerbations, and among children, having any exacerbations is associated with a greater rate of decline in the ensuing 3 years. Improved prevention, identification, and treatment of pulmonary exacerbations are likely to have long–term benefits for patients with CF, especially children.
http://tinyurl.com/2ea9vet

Evaluation of a novel sputum clearance technique-hydro-acoustic therapy (HAT) in adult patients with cystic fibrosis: A feasibility study. Jarad, T. Powell, E. Smith. Chronic Respiratory Disease. November 17, 2010 vol. 7 no. 4 217-227

The study was designed to investigate the efficacy, safety and patients' acceptance of a novel system for sputum clearance – Hydro Acoustic Therapy (HAT) in patients with cystic fibrosis (CF). HAT was found to be safe, well tolerated and favoured by the majority of CF patients. The effect of HAT, however, on sputum production was not superior to flutter or placebo.
http://tinyurl.com/2bhbceg ▲

Laura is 63 and has CF. She is a Director of USACFA and is the President. Her contact information is on page 2.

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
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In Memory

Emily Kathryn Haager, 27
Diamond Bar, CA
May 1, 2010

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

Call to All Artists

If you wish to submit art that expresses your feelings about CF or anything on your mind, please send photographs of any media: paintings, illustrations, collages, drawings, sculpture, etc. to:

cfroundtable@usacfa.org. or you may mail them to:

USACFA
PO Box 1618
Gresham, OR 97030-0519.
Please include your name and contact information.

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Do you wonder when your *CF Roundtable* subscription is due for renewal? Have you wondered how to tell if it is time to renew? Look at your mailing label. Immediately after your name, there should be a date. That is your renewal date. (On the example, you can see that Kathy is due to renew her subscription in May 2011.) If there is no date or it says (COMP COPY), your subscription is due for renewal.

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Thank you for helping us with this.

Subscription Changes for the New Year

After much deliberation and discussion, the USACFA Board of Directors has decided to make some changes. Starting in 2011, we are asking for a little larger annual donation from our subscribers. For the past 20 years we have requested that subscribers donate $10 per year. Since printing and mailing costs continue to rise, we now will ask $15 per year as an annual donation. We hope that this won't prove to be a hardship for our readers. For corporate subscriptions and those that are sent to addresses outside of the USA, we request an annual donation of $25. As always, *CF Roundtable* is available at no cost to those who are unable to make a donation.

REMINDERS

- Please notify us immediately of any address changes. Returned mail wastes money and delays mailings.
- To keep our mailing list current, we require the completion of a subscription form every year, even if you are unable to make a donation. Your address label indicates when it is time to renew. Subscriptions stop automatically if not renewed regularly.
- 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 or fax at **(503)669-3561**. (That number always answers by machine.) You may email 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. Email: cflegal@cff.org**.

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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.

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http://www.trioweb.org/index.shtml
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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

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