CF Roundtable

A NEWSLETTER FOR ADULTS WHO HAVE CYSTIC FIBROSIS SUMMER 2008

You Can Help Us

The United States Adult Cystic Fibrosis Association, Inc. (USACFA) was organized in 1990. The first issue of *CF Roundtable* was mailed in late 1990. We have published 70 issues, since then. (This is our 71st.)

We always have asked that, if possible, people donate $10 per year toward our costs. We request that corporations and institutions donate $25 annually. Initially, we asked subscribers from other countries to donate $15. As postage costs continued to rise at a rapid rate, we had to increase that request to $20 per year for addresses outside the USA.

Now, we find that with the continued increases in costs of printing, mailing and other expenses, we need to raise more operating capital. Many of our subscribers have been wonderful about including "a little extra" with their subscriptions. We really appreciate that. Also, we understand that many of us are unable to send even $10 per year. As long as everyone sends in a completed subscription form, once each year, we have continued to mail the newsletter to them and we hope to continue doing that.

We always have tried to be careful to not cut into the fund-raising bases of research organizations such as: the CFF and CFRI. We don't want to keep any funds from going to research.

However, we feel that *CF Roundtable* provides an important service to many people. *CF Roundtable* is read by more than only those who have CF, their families and their friends. It is read by physicians, researchers, nurses, respiratory therapists, social workers, and many other folks who just have an interest in CF.

For many adults who have CF, *CF Roundtable* provides their only connection to others who have CF. It provides a support network for many people. It is a way that we all can share information, questions and friendship, without having to worry about cross-infection issues.

We can't cut salaries, because we all are volunteers. Since we all work from our homes, there is no rent to cut. But there are ways that we can cut our costs. For instance: We could stop having any color photographs. We even could go back to printing in black ink, only. We could go to a lower grade of paper and use white, rather than the cream that we always have used. We could limit the size of each issue to a certain number of pages. We could stop sending the newsletter to anyone who hasn't sent in a subscription form in the previous 12 months. But we don't want to do any of these things.

We would like to continue publishing a full newsletter that has color and lots of information. We definitely don't want to have to drop anyone from the mailing list. We want to continue to provide a forum for adults who have CF to be able to share their ideas, concerns and interests.

You can help us by sharing information you may have about any contacts where we could access funding for continuing our efforts. We don't need a lot of money. We need only enough to keep providing a service to the community of adults who have CF and to their families, friends and care givers. Thank you for your help. ▲

INSIDE THIS ISSUE

See our website: www.cfroundtable.com

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USACFA needs your tax-deductible donations to fund the printing, production and mailing costs of *CF Roundtable*. A yearly donation of $10 for individuals, $20 for non-U.S. addresses (U.S. funds only) and $25 for institutions is requested. However, *CF Roundtable* always is free of charge to those who are unable to donate. Back issues are $2.50 per copy. A fully completed subscription form is required to add your name to our mailing list. (If you have CF, please include your birth date.)

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.

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A WORD FROM THE PRESIDENT...

Two thousand eight has been a tough year for most people. The costs of fossil fuels and other commodities continue to skyrocket, healthcare costs continue to increase, and the value of our homes, if we own them, continues to drop. As an organization, USACFA also has fiscal responsibility, and we, too, are struggling to manage our costs. I urge you to read our front page article and think about ways you could help us out.

My year has seen more negatives than positives. My father was hospitalized for 40 days beginning March 4, and my personal health issues also grew into new dimensions. I am happy to say that both my father and I are fighters and we continue on the road to recovery over the challenges we face. We get this done with our attitudes and the prayers offered by so many. Thank you, all.

A continuing discussion on attitudes is well reflected in **Julie Desch's** *Wellness* article. It not only expresses the positive attitudes her dog Cisco and she display, but shows the value that support people, or animals, have on each other, and how new technology can help all of us. I enjoyed pre-reading **Rich DeNagel's** *Unplugged* interview with Jerry Cahill. I've met Jerry a couple times; our life journeys have much in common, and our ages are within months of each other. I found during Jerry's interview that many responses he gave were similar to my own. **Isabel Stenzel Byrnes** authors *Spirit Medicine*, discussing the connection between the spirit and the physical body that CF helps form. I'm sure her words will hit home for many of you, as they did for me. In *Ask the Attorney*, **Beth Sufian** answers two common questions most of us have at sometime during our life and provides continuing information on SSI benefits. Our focus topic this issue is *"New Products and Equipment that Make Our Lives Easier"*. In *Speeding Past 50*, **Kathy Russell** discusses a half-dozen products that have made her life easier and may be something you want to consider. In an interesting twist, **Jean Hanley** discovers a new use for a device most people with CF rarely would use. You have to read it to believe it. **Debbie Ajini** begins the first in a series of articles about her prospects of getting listed for transplantation, despite some obstacles she faces. This should be an educational series for anyone considering transplant. **Katrina Bischoff-Howell** provides her opinion of the book *"Sick Girl Speaks: Lessons and Ponderings Along the Road to Acceptance"* by **Tiffany Christensen.** Are you a twin with CF? Please consider participating in the study *The Search for Modifiers of CF – The US CF Twin and Sibling Study*. Finally, read about **Richard Weiss,** the latest *'Hero of Hope'*. You probably have heard something he once said.

In three days I leave to participate, once again, in the US Transplant Games in Pittsburgh. I wish good luck to all athletes; and another round of sincere thanks to our donor families!

Peace,

Paul

Publication of *CF Roundtable* is made possible by donations from our readers and a grant from CF Services Pharmacy.

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

Katrina Bischoff-Howell
Carlsbad, CA
38 on June 5, 2008

Ray R. Corwin
Jacksonville, FL
47 on June 28, 2008

Richard DeNagel
San Francisco, CA
40 on July 5, 2008

Paul Feld
Florissant, MO
51 on May 9, 2008

Philip Howell
Carlsbad, CA
51 on June 7, 2008

Kurt Robinson
Corvallis, OR
25 on July 7, 2008

Wedding

Debbie & Louie Ajini
Shelby Township, MI
13 years on June 17, 2008

Isabel & Andrew Byrnes
Redwood City, CA
10 years on June 27, 2008

Paul & Kristi Feld
Florissant, MO
17 years on June 1, 2008

Katrina & Philip Howell
Carlsbad, CA
14 years on June 25, 2008

Beth Sufian & James Passamano
Houston, TX
20 years on July 2, 2008

Laura & Lew Tillman
Northville, MI
33 years on July 18, 2008

Transplant

Anabel Stenzel, 36
Redwood City, CA
Bilateral lung transplant
8 years on June 14, 2008

Work

Kurt Robinson, 24
Corvallis, OR
Promoted to Assistant Manager
Platt Electric Supply
Corvallis, OR
April 2008

NEW BEGINNINGS

Wedding

Cynthia Dunafon & Steven Holloway
Chicago, IL
Married on May 23, 2008

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**

Summer (current) 2008: New Products and Equipment that Make Our Lives Easier

Autumn (November) 2008: Organ Transplants (Submissions due September 15, 2008.) Tell us of your transplant experiences. How did you make the decision to have transplant and how have you done since the surgery?

Winter (February) 2009: Love, Dating and Marriage. (Submissions due December 15, 2008.) Have you run into problems with relationships because of CF? Do you have any advice for people who are dating? When do you tell someone you are dating that you have CF? Give us your insights.

Spring (May) 2009: Making Career Choices with CF. (Submissions due March 15, 2009)

ASK THE ATTORNEY

Questions from Readers

By Beth Sufian, Esq.

The following is a compilation of questions asked by readers of *CF Roundtable*. Questions asked by readers never are disclosed without the agreement of the reader and information never will be published that would allow anyone to identify the reader who asked the question. Nothing in this column is meant to be legal advice about your specific situation. If you have additional questions please contact Beth Sufian at the CF Legal Information Hotline at 1-800-622-0385. The Hotline provides free and confidential legal information to people with cystic fibrosis, their CF Center care teams and their families. The Hotline is sponsored by the CF Foundation, through a grant from Novartis. The Hotline can also be reached by e-mail at: CFlegal@cff.org.

1. How can a person with CF obtain a life insurance policy?

There are no federal laws or regulations requiring access to life insurance for people with cystic fibrosis or laws that would require life insurance be sold to people with medical conditions requiring ongoing treatment. The Americans with Disabilities Act specifically excludes insurance from its mandate of certain protections for people with disabilities. There are some insurance agents who tell people with CF to obtain a letter from their physician stating that the person only has a "mild" form of the disease, in the hopes of being able to obtain a life insurance policy for the individual. Typically, the person with CF has the application for life insurance denied even if such a letter is provided. The best and most likely way a person can obtain life insurance is to work for an employer who offers life insurance to employees. Larger employers often offer life insurance to employees without a medical test or the need to show good health. There are no federal laws that require an employer to offer life insurance to employees. However, for people with CF, an employment-based life insurance policy is going to be the way to obtain such a policy. There have been

BETH SUFIAN

people with CF who have been able to obtain a life insurance policy that will pay a benefit if the policyholder's death results from an accident and not from CF. If a person with CF has the funds to purchase a life insurance policy based on accidental death, that may be advisable.

2. Can a person with CF obtain a home mortgage?

Eligibility for a home mortgage will depend on income and credit history. A diagnosis of CF should not affect mortgage eligibility. However, there are some mortgage lenders who require that some applicants obtain a life insurance policy that will pay the mortgage in the event of death of the mortgagee. This happens in a limited number of situations. As the answer to question number one indicates, it will be very difficult for a person with CF to obtain a life insurance policy on his own that will pay a benefit if the person dies due to CF-related medical complications.

3. If I make more money than the SSI income limitations can I still keep Medicaid?

NO! SSI is an income-based government program. Therefore, in order to remain eligible for the program, a person must meet certain income requirements and certain medical requirements. Medical eligibility is typically reviewed by Social Security every 3 to 5 years. However, income eligibility can be reviewed every week, every month or every year. A single person must have less than $2000 in assets and is limited in the amount of money that can be made from work activity. Unfortunately, some people with CF think that their need to use expensive medication will allow them to keep the Medicaid benefit that they are receiving by virtue of being on SSI, even if they lose eligibility for SSI benefits. This is untrue. If a person loses SSI benefits the person will lose Medicaid benefits. Most states do not offer Medicaid to people over 21 years-of-age, unless the person is also receiving SSI benefits. The fact that a person with CF needs to use expensive medications to fight the disease does not matter in

"Efforts should be made to make sure that SSI eligibility is maintained so that Medicaid eligibility is maintained."

terms of income eligibility for SSI and Medicaid. However, there are times when an SSI recipient can use out-of-pocket medical expenses to increase the income limitations. For example, if a person with CF pays $20 a month out-of-pocket for vitamins, SSA may increase the individual's income limit by $20. The person with CF should discuss any out-of-pocket medical expenses with a Social Security representative.

Efforts should be made to make sure that SSI eligibility is maintained so that Medicaid eligibility is maintained. There are certain SSI programs that allow a person to make more than the typical allowed amount from work activity and still retain benefits and Medicaid. The next column will provide information on such programs. Social Security is very good at keeping track of the assets and income of SSI recipients. Social Security representatives have access to information from the IRS and easily can determine if a person has over the $2000 in assets, by reviewing bank records or reviewing 1099 forms filed by employers that indicate the amount of income made by an individual. It is important to understand the income limitations and to make sure that income does not exceed the limitation. Likewise, a person with CF who is receiving SSI and who gets married will have to make sure that their new spouse's income does not put them over the household income limitations for a married couple. ▲

Beth is 41 and has CF. She is a Director of USACFA. Her contact information is on page 2. You may send her questions of a legal nature that are CF-related.

CF Living: An Interactive Source for CF Information

Here is another resource that can help one stay up-to-date with the latest CF treatment information. The resource also offers support services for patients and caregivers and other specialized information that can make coping with CF a whole lot easier.

Check out *CF Living* (www.CFLiving.com), a free, online program that delivers customized educational material and resources to help people with CF and caregivers alike. Full of practical information, including tips for making the most out of healthcare appointments and staying compliant, *CF Living* provides a convenient way to stay informed about CF and helps you to work more closely with your CF care team.

By enrolling in *CF Living,* registrants will be able to take advantage of the following:

- ***A Personalized Care Team Discussion Guide* with tips for how to engage in an open dialogue with your Care Team members, along with suggested questions to help start an informed conversation**
- **A series of educational e-mails to help you learn more about cystic fibrosis and what can be done to manage it**
- **Access to online resources that may help you continue to learn about CF**

To enroll in *CF Living* or learn more about the program, visit www.CFLiving.com. The program was created by Genentech, Inc. as part of the company's continued commitment to providing information and resources to individuals with cystic fibrosis and their caregivers.

SPIRIT MEDICINE

The Spirit of the CF Body

By Isabel Stenzel Byrnes

My inspiration for this Spirit Medicine article comes from a favorite episode of "King of the Hill". Peggy Hill's annoying Laotian neighbor saw Peggy's shoes and exclaimed, "Oh, my, Peggy Hill, what big feet you have, like boat!" Peggy replied, matter-of-factly, "Well, that's just the way God made me."

I really admire Peggy's acceptance of her body. As someone living with cystic fibrosis (CF), I've spent a good amount of time fighting my body. I don't mean fighting, literally. I mean fighting my disease, with treatments and medications. I mean a harder fight; that is, lamenting, even hating, my body. Though I have had good days and bad days, there have been many times where I wished I was born with a different body, not this lemon that required constant tune-ups.

Facing my feelings towards my body is part of healing my spirit. I believe negativity towards my body affects my spirit. To have a healthy spirit, I want to come to terms with my body, whether it is healthy or not. I am trying to make friends with my body. I've come a long way, but acceptance is a gradual process.

I confess my body-dread only with the trust that there are others out there who share similar sentiments. Many people with cystic fibrosis are plagued with their fair share of physical harassment. Many of my CF friends have said, "If it's not one thing, it's another." If the lungs are good, there are intestinal problems. If the stomach is good, the sinuses are bad. There's always something going on! This can be the case even after a lung transplant.

I recognized that everyone - healthy or not - is burdened by some aspect of the body. Earlier this year, I went to a Broadway show with my CF friend, Jerry Cahill. We saw the musical "Spring Awakening", and one song struck a chord with me: "The B**ch of Living". It was about the torment suffered by teenage boys because of their relentless sexual desires. While I found the song comical, it proved to me that everyone - even healthy, vibrant kids - has something to gripe about when it comes to our physical bodies.

Still, though, CF is particularly insidious. CF affects my lungs, gut, belly, nose, liver, cheeks, hearing, teeth, taste, smell, hair, muscles, bones, sweat, weight and hence chest size, voice, nails, libido…the list goes on.

When I first started dating my husband, Andrew, we asked each other, "What part of your body is the most attractive?" Andrew answered that he liked his eyes, because of their unusual blue-gray color. I agreed, and told him something cheesy, like how eyes are the windows of the soul. Then it was my turn to answer the question. I thought long and hard about the question, and finally thought of the only part of my body that wasn't flawed by CF: my skin. So, I told him I liked my skin. It was smooth, soft and tan. Andrew liked my skin, too.

Today, though, I hate my hands. For decades they were cursed with embarrassing clubbed fingers. Now, I've been blessed to be transplanted. I can breathe again. My clubbed fingers went away. However, after living four years with immune-suppression, my hands are covered with an unwanted hitchhiker: warts. Each month I live, I get a new wart. I guess I really shouldn't complain! But, "There's always something," and, recently, my warts

ISA STENZEL BYRNES

were burned off, creating stingy, oozing blisters that look so horrible that I have yet to show my hands to my husband or friends. Once again, CF has indirectly affected my once-attractive skin.

Okay, I'm human, so I allow myself to wallow and whine for a period of time. Then, there's a time to shift to a healthier place of being. I invite myself to look at the positive parts of my body. This is my first step to body acceptance.

First, I celebrate what works in my body. As a transplant recipient, I am very blessed with good health. It's a lot easier to love my body now that it works! I mourn the fact that this body nearly ended my life a few years ago, but I celebrate being healthy enough to hike, run and swim now. But whether I have healthy or sick lungs, other parts of my body work just fine. My eyes allow me to gaze at gorgeous landscape. My vocal cords allow me to communicate; my ears allow me to enjoy beautiful music. Even my ugly hands allow me to touch Andrew and type words for this essay.

I also look at the many good things that come from my CF body. Before my transplant, my strong chest muscles, even my barrel chest, allowed me to cough up the poison that was killing me. I had an awesome six pack of abs. My arms grew muscular pounding on my sister's chest. I was spared an annoying period for a long time. And still now, my sickly pancreas makes me crave delicious food and allows me to eat more than a 200 pound man. My robust colon can handle a whole lot of you-know-what.

Another positive aspect of my high maintenance body is that it gives me the opportunity to pay attention to the dialogue between my body and spirit. Each time I get sick, my body kicks up the fight, and my body's spirit feels stronger. I give in to the demands of my body by offering rest, medicine and nourishment. The body responds.

I am also grateful for what my body teaches me. I know my body won't last forever, so I have to appreciate every day. It doesn't matter what clothes my body wears, how I paint my face or decorate my body, because I am not my body. My body just allows me to fulfill deeper desires in life. I want to love, to serve others, to enjoy nature, to see the world, to give affection to others, to wonder about God; and to do all these things, I must have a body. And this is the one I have.

A major moment of bodily acceptance was when I saw my CF lungs in the pathology lab after my transplant. I was filled with awe, respect and even affection for the grotesque lungs that sustained me for 32 years. I said goodbye with a reverent, "You done good."

> *"To have a healthy spirit, I want to come to terms with my body, whether it is healthy or not."*

Reading the pathology report that said, "No evidence of functional lung tissue remaining," made me wonder how I had the strength to survive with CF for as long as I did. My circumstance is just one example of the strength of the CF body in general. I believe people with CF have inherited a tremendously resilient physical nature. I've met some pretty hardy people with CF.

Our physical challenges fuel a passionate drive to truly live. One friend with CF climbed Mt. Kilimanjaro and scuba dives. Another friend runs marathons. One CF teen swims competitively in "Laps for CF". Talk about resilience! I am in complete awe of my CF friends whose sick bodies have made remarkable comebacks. One friend had a lobe removed due to hemoptysis, only to backpack in Nepal a year later. Another woman I know gave birth to a baby three months before receiving a bilateral lung transplant. Our CF bodies are amazing! Another friend survived a bilateral lung and kidney transplant. Now that's tough.

I must acknowledge that some people with CF are not so lucky, and face unending physical battles. Just eating a meal or walking a block is a struggle. It is completely justified to lament the horrible suffering that CF causes. When I had end-stage CF, I didn't think my body was amazing. It was just awful. But looking back, I think my body deserves some recognition for its stubborn persistence to keep going. The same could be said for others with advanced CF. I've known some people with CF who have worked full-time for years with lung capacities in the teens. After my sister's second lung transplant, a nurse complimented, "You just don't die!" (At least for now.) Likewise, one friend was placed on a ventilator, taken off the ventilator, and went back on and off before being transplanted. What a fight to survive! No matter how sick someone is with CF, there is still more working in our bodies than not; or else we'd be dead. If we're still breathing, there is life. Many of you reading this probably have your own survival stories to share.

Sometimes, no matter how resilient our bodies are or how strong our drive to survive, our bodies fail us. Our final relief from bodily suffering comes with death. This is the ultimate cruelty of our disease; and a forced acceptance of the limitations of the body. I do not believe death is a weakness of the body, but a reminder of our finiteness and powerlessness. When I reached the end of my CF lung disease, it was a rude awakening that I was not in control and

Continued on page 23

WELLNESS

Run, Walk and Roll

By Julie Desch, MD

I know that I promised an article on the energetics of exercise. And I will do that…I promise. But when I looked at the Focus topic for this issue of *CF Roundtable*, "New Products and Equipment that Make Our Lives Easier", I thought of my dog. So, I'm going to exert my right as a woman to change my mind. Exercise and energy are to follow. For now, sit back. I have a story to tell you.

It's a hot, summer day last August. The "world's champion" (not really, but we thought so) Frisbee™ dog, my 13-year-old Border Collie, Cisco, is out in the back yard chasing squirrels with his two schnauzer brothers-from-another-mother, Wiley and Jaxon. This is their favorite game, and I am watching them from my glass-enclosed office, where I am sucking on some hypertonic saline. Cisco has been the most athletic dog I have ever known…literally winning regional Frisbee catching competitions, running with me wherever and whenever I go, defying any and all attempts to contain him his entire life by either jumping fences or opening gates. I kid you not; he could star in his own television show with episode after episode of tales of his pure determination and ingenuity in fulfilling his life's work: *never* letting me out of his sight.

But this day, he knows I am safe, and his focus is on the squirrel above him, taunting him from the telephone wire. Another squirrel joins the game from the edge of the yard, and the schnauzers are off like lightening, tearing across the grass at a speed I didn't know was possible. Cisco starts to follow, and then I hear the most heart-breaking and terrifying scream emit from his mouth as he flops on his back and writhes in agony. It takes me two nanoseconds to get to him, and less time than that to realize that he is in serious trouble. He clearly can't move his back legs, and I can literally smell his terror in the air.

Fortunately, the boys are with me, and we get him in the car and to the vet as fast as we can. One X-ray later, we are rushing to another veterinary office, where they specialize in back surgery. I get the news there: he has ruptured a disk in his vertebral column, and he needs immediate surgery to decompress his spine. He will "likely" be able to walk again, but every second that passes decreases the chance of significant recovery.

There I am with two young and very upset kids and a dog that is like another child to me, barely looking at the price estimate. You can't place a price on my relationship with this dog. He's been through thick and thin with me. For thirteen years, he *always* has been there for me, and now I needed to be there for him, big time. I call my partner, and we decide…we'll figure out how to pay for it later.

Days later, we take him home. The few weeks that follow are a bit of a blur. I nurse that dog like a baby. I learn how to "express" his bladder because those nerves don't work at first. I put diapers on him, and "chucks" under him, often to no avail. I get peed on and pooped on and even nipped when he was hurting, just like old times with the boys! I even put my pillow down on the ground next to him and sleep with him at night, holding his paw and stroking him so he knows I'm there…otherwise he cries and neither of us gets any sleep. I carry him everywhere because if I leave the room for a minute, he starts yelping, "Mommy… where did you go???" in dog. Forty-three pounds of limp Border collie is a LOT of weight to move ten times a day, and I am very appreciative of all the dead lifts I've done at the gym.

Then, physical therapy starts (think "ka-ching"). I learn to "walk" him using a

> *"I even bet that some of you, who think you can't run, can build up to a jog."*

JULIE DESCH AND HER DOG CISCO LEARN TO USE THE NEW "WALKER".

sling for his rear end. He gets massages, and TENS, and learns to walk on an under-water treadmill. The therapists and I actually re-teach him how to walk again, by moving his back legs over and over again in a bicycle motion and flexing and extending his bad leg over and over. Then, one day at therapy, he struggles to his feet by himself and sort of pulls himself by his front paws across the room toward me as his back legs stagger and slide. He moves about seven steps before he falls down. It definitely wasn't pretty, but this is the first time he is able to move on his own accord and we cheer and scream for joy. I swear he's smiling!

Winter comes, and I have probably my worst cold season ever. I've got a PICC line in for many, many weeks and am having other health issues recovering from a deep vein thrombosis (DVT) in my arm. Still, Cisco and I make our daily treks around the neighborhood. There we are… I'm coughing and infusing, and my faithful boy is limping and sliding along at about the speed of a slug. Sometimes it's not clear who is taking whom out to walk, but nothing keeps us from our daily treks.

As I write this, it is summer again, and I am happy to report that Cisco is still with us, as a much older (functionally) and much lighter and greyer version of his old self. His back hips and legs have atrophied down to the bone. He's recovered some of his strength, but still needs assistance with his "morning constitutional" (which, by the way, is a total misnomer…it happens at all times of the day). Every morning, afternoon, and evening, Cisco and I go for our stroll around the neighborhood, him hobbling slowly but with as much dignity as he can muster with me holding up his butt with a sling. When he sees other dogs, he still growls with the best of them, and, oddly, seems to forget that he is disabled as he tries to chase them down, dragging his left leg (and me) behind him as I desperately try to keep holding the sling.

This is similar to me doing push-ups and yoga with the PICC line in (did I mention I developed a DVT?). Anyway, the point is, you can't keep us down. We are there for each other, and we are quite a pair! End of story.

> *"If you still are breathing, you can do something!"*

Why am I telling this story? What in the world does it have to do with cool equipment and technology that makes life easy? Well, Cisco and I were chatting just the other day. It turns out that we both are getting rather tired of going around the same old area, the same houses, the same trees and plants. We both want to go to new places, see new things, growl at new dogs. But he just doesn't have the stamina to go too far from home.

So I made him an appointment to get fitted with a K9-cart. These are so cool! They are "wheelchairs" for dogs. You put the dog's hindquarters in a type of sling, and they pull themselves around on wheels! He's going to be so happy. I can't wait to get it.

Finally, we are back to why I wanted to tell this story. I once told my partner, who was trying to convince me that long distance running may not be my best exercise option, that I *had* to run….well, jog. I used to run. I ran until I couldn't anymore. Then, I started to jog. Then, the continuous jog became a jog/walk. This is where I'm at now. When I can't do that anymore, I will walk. When that becomes too hard, I will walk very slowly. When that becomes too difficult, I guess I'll roll (but I'll pull myself along).

Cisco is the dog model of exactly the way I plan to do it. He used to run like the wind. He could jump tall buildings. He could open any door. He could do crossword puzzles. He was Cisco, the Wonder-Dog. Now, he drags himself around, limping after me, wherever I go. He uses mostly his front paws and stumbles and falls quite a bit, but unless there is a need to squat (as I referred to above,) he gets around on his own. Not only that, but he still tries to chase the schnauzers around the yard, squeaking his ball like crazy while they wrestle. It's becoming hard for him, though. He's decided it's time for some assistance, and I agreed. Now we'll roll. Well, he'll roll. I'm still jog/walking for a while longer.

So maybe you can't run. I bet you can walk. I even bet that some of you, who *think* you can't run, can build up to a jog. Or maybe you'd be happier on a bike…or roller blades…or swimming in a pool. If you still are breathing, you can do something! Even if your breathing is labored, or you have problems with desaturation with exercise, they make some awesome portable O_2 tanks these days. Not only that, but there are portable O_2 saturation meters that you wear on your finger so you know how much oxygen you need! There are heart rate monitors, portable blood glucose meters, GPS devices…you name it! Check out Jerry Cahill on You Tube as he takes his oxygen tank for a run (http://www.youtube.com/watch?v=dT6aEuZKpC4). Take a cue from Cisco, and from me, and from Jerry: Keep moving, no matter how it looks, and keep squeaking your ball. ▲

Julie is 47 and is a physician who has CF. You may direct your questions regarding CF-related health issues to her at: jdesch@usacfa.org.

SPEEDING PAST 50...
Little Things Can Mean Big Help

By Kathy Russell

KATHY RUSSELL WITH HER NEW TREK-S AND PARI NEBULIZER.

At long last, we are having some warmer weather. It seems that we have had one of the coldest (for us) and longest (again, for us) winters on record. Usually, by mid-February we are enjoying warming days and the first signs of spring. This year, in early June we still were having snow at some elevations! Of course, we are much more fortunate than all the people that were displaced by tornadoes or floods. Every time I see the destruction throughout the midwest, I am brought to tears. I do hope the farmers can salvage some of their crops and that people can get back into their homes or replacement homes, soon. Also, I hope that the fires in northern California can be controlled.

I noticed that the Focus topic of this issue is *New Products and Equipment that Make Our Lives Easier*. Let me tell you about some of the items that make my life easier. I am sure that many of you are familiar with the PARI Trek®-S nebulizer system. It has been around for a while. I got my first one last year. My old PARI Dura-Neb 3000 finally gave up the ghost. I hated to see it go, but such is life among compressors. I received the Trek-S system in August. It is such a small unit that it fits almost anywhere. It weighs just over one pound with the battery attached. The battery is rechargeable and there also are adapters for household or automobile current.

The Trek-S comes with its own carrying case and can be worn like a purse or pack for ease of use. It has pockets for the cords and a nebulizer. When it is closed up, it looks just like any other small pack and doesn't look at all "medical".

I use the Trek-S with the PARI LC Plus nebulizer. My Pulmozyme® treatment takes only about ten minutes with the Trek-S and the LC Plus. This provides a distinct advantage over older, slower neb systems. Any time we can save on our treatments gives us more time for other things.

The people at PARI are very helpful. When my first Trek-S died, recently, I called PARI and was told to return it and was given a reference number to put on the package with my return address. I sent it off and received a new one within ten days. I appreciate the service. They can be reached at: www.PARI.com or 1-800-327-8632.

Another piece of equipment that I use every day is *The Vest*® chest percussion device. It allows me to do my lung clearance while I read my e-mail or play computer games. I get good therapy and am able to take care of another task while doing it. The people at Hill Rom, who work with the vest, are knowledgeable and very willing to help. I have called with varying requests or questions and always have gotten quick and friendly service. When I asked for a different size vest, I received it the next day! I have been using my machine for over 1200 hours and have had no service needs on it. Reach them at: www.thevest.com or 1-800-426-4224.

I always am concerned with maintenance and cleaning of my equipment. The PARI Trek-S and The Vest need only to be wiped off with a damp cloth, occasionally. The PARI LC Plus takes a little more work. After each use, I dismantle it and rinse it in hot water. Then I soak it in a small dish with hot water and a little bleach solution. When I take it out of the solution, I let it air dry in a basket that is just for nebulizers. The soaking dish that I use is a disposable, plastic storage dish. I think it may be a Glad® or similar product. It measures 4 ½" by 6" and is about 2 ½" deep. It can go through the dishwasher and is very inexpensive. It packs for travel very easily.

My newest acquisition of major equipment is an Inogen One portable oxygen concentrator. This is the greatest little device. It weighs only about 17 pounds, with its rolling travel case, and

it provides up to five liters per minute of O_2. It is made so that it can be pushed or pulled. I find that it is handy for holding my purse and anything else that I don't want to carry. It comes with household and auto adapters, as well as a battery. (It is globally compatible, when you have the correct adapters for outlets in other countries.) The carrying case can hold all the adapters and extra batteries.

It is accepted for use on most commercial airlines. The batteries each last about three hours, at three liters per minute, and they are rechargeable. If one is going to use it for commercial airplane flights, it is necessary to have enough batteries to last about twice the duration of the flight. (This is in case there are delays. As if that ever happens!) It even has a four-pin adapter that can plug into the computer power port that is available on some planes. The battery must be removed while it is plugged into a plane's power port.

I have not yet taken it on an airplane but have talked with others who have. They all have said that it worked fine and was easy to use. I do know that United Airlines does not yet accept personal concentrators. I have read that they will have to start accepting them next January. I surely hope they do.

I have found another new item that eases my life. In early April we were in an auto accident and my head and back got "whacked". I have been going to physical therapy for that since the first week of April. Although my back is getting better, I still need a little extra help for it. When I went to a medical equipment pharmacy, to look for heat packs, I found a great item. It is a plastic pack that is about a half inch thick and is filled with a gel. The pack is called Therapy Gel. It can be heated in the microwave or cooled in the refrigerator or freezer. The one I got is 10" by 15" (the right size for my back) and provides a flexible method of getting heat to the sore muscles. I noticed that they have these packs in various shapes and sizes. Since many of us deal with sore joints and muscles, I thought you might be interested. They can be reached at: www.calderaintl.com or 1-800-581-1200.

While I'm thinking about joint or muscle pain, I remember that I have another piece of equipment that really makes my life easier. My hands ache. Sometimes my thumbs don't want to work. My husband got me a paraffin bath for my hands. It is a small appliance that holds a couple pounds of paraffin and keeps it at a comfortable temperature. I dip my hands into the paraffin, let them cool a little, dip them again, and repeat until I have a good coat of paraffin on them. Then I put my hands into special plastic bags and wrap them up in a towel. I let the heat work for ten to 20 minutes and undo them. It always makes them feel better. I could use it for feet, if I wanted. I love it!

Also on the theme of muscle pains – I use a back support belt, like you see employees at warehouse stores or Home Depot wearing, to help support my back when I am coughing a lot. I find that when I am coughing so much, and so hard, my muscles start to get weak and are of little help. When I use the support belt, I am able to cough, productively, without needing any extra help from my husband. (Before I had the belt, if my muscles got too weak, my husband would put his hands around my lower thorax, to lend support with coughing.) The belt is a real plus when I am alone.

I know that I have mentioned before that I use custom earplugs, when doing my treatments, but I think it warrants mentioning again. My ENT was able to get custom plugs made for me and they protect my ears from loud noises. Since I spend about an hour and a half each day with nebulizers, and compressors, and the Vest, my ears are subject to lots of noise. The plugs filter out the harshest noise and allow me to hear normal sounds. I wear them when I fly, too. They cut out the noise of the plane's engines but still allow me to hear conversation or a movie. They are small and they have their own carrying case. The case fits in my purse, easily. They were not expensive. When you consider that they can save your hearing, they really are not expensive!

The last piece of equipment that I want to mention is my WaterPik® for sinus irrigations. It has saved me from sinus surgeries, I am sure. I use a warmed sterile normal saline irrigation first, and then I add a little solution of glacial acetic acid to some more of the saline, for the final rinse. I use a specially modified tip for the irrigations. Since I am able to control the pressure, I am able to get out all the various crusts and "junk" that accumulates in my sinuses. This therapy must be used only with the supervision of an ENT doc. Since using this therapy, I have had no more polyps and no more sinus surgeries. Hooray! If anyone wants to know more about this procedure or about the WaterPik and special tips, you can contact me.

So, there you have it. Some of my equipment is fairly new while other pieces are not. If you didn't know about any of these items, prior to reading it here, it is all new to you. I hope you find something of interest.

We all know that many of the things we must use can be very expensive. If those things improve our lives or keep our health from deteriorating, then they are well worth the prices. Some of our "helpers" are small while others are larger. Even the little things can mean big help. I hope that researchers will continue to look for new ways for us to use the meds that we need and to make doing our various treatments easier. We're rooting for you.

Stay healthy and happy, ▲
Kathy

FOCUS TOPIC

NEW PRODUCTS AND EQUIPMENT THAT MAKE OUR LIVES EASIER

Microphone Stands Are Not Only For Singers

By Jeanie Hanley, MD

JEANIE HANLEY, MD

Like you, I have and employ all the usual, wonderful life-saving devices, machines, and medicines. Every item I use is critical for my health. I know this because I've tried to go without or use less of each of them at some point or another, only to find out that, "oops!" I really do need that medicine or the Vest or whatever at that dose, frequency, etc. So, aside from the usual then, what is there? Answer: the unusual. For me, that is a microphone stand. I know what you're thinking. What is she talking about? Does she know what this newsletter is all about? Or, is she secretly thinking about auditioning for "America's Got Talent"?

As it so happens, "America's Got Talent" will have to wait a little longer for the CF Crooner. And just in case you're wondering, I'm in fact using the microphone stand to hold up the nebulizer cup as I write this article, inhaling one of my many medications, with the VEST pounding and the compressor humming away. Perhaps I should explain how I got here.

About one year ago, my neck started bothering me. I seriously did not think twice about it. Honestly, what is one more small pain in the neck for those of us with CF? About two months ago, that pain became very severe across the back of my lower neck and radiated to my shoulder blade and left arm. Being a physician, I immediately checked my pulse, breathing, blood pressure, and oxygen saturation via pulse oximeter. Okay, at least I wasn't having a heart attack! And my lungs appeared to be working as well as could be expected.

I figured it was just stress and thought very, very deeply about who was a real pain in the neck and therefore, could be responsible for this. Hmmm, whom could I blame? After several moments, I could not come up with a good candidate, so I performed a few yogic maneuvers and stretches, and then tried very hard to ignore the pain once again. This time, however, it was not so easy. After having several sleepless nights resulting from a lack of a comfortable position due to the stabbing pains now in the neck, shoulder and back, I went to see a neurologist.

I was sure it was either cervical spondylosis or herniated nucleus pulposus or radiculopathy or a cerebral malignancy (arthritis of the neck, slipped disc, pinched nerve, brain cancer, respectively). Ok, ok, I didn't really think I had cancer but I was also desperate to find the source of my problem. Since my favorite neurologist was on sabbatical, I was left at the mercy of referrals. A col-

> "As CF patients, [we] are particularly susceptible to experiencing other aches and pains unique to frequent, prolonged nebulizer use."

league recommended a neurologist who, not surprisingly, did not know much about CF in adults, but he also didn't seem to want to learn about it, especially the part about many of us having a very high pain tolerance. When we say something hurts, it must be very severe!

On the day of the office visit, I arrived very tired due to the sleeplessness and pain during the night and, as so often happens when you finally get to the doctor, the neck pain had inexplicably subsided considerably that morning. After describing and emphasizing how severe the pain had been in my extremely fatigued voice and body during the exam, the neurologist concluded that whatever it was, it was mild and suggested that I should try some massage or physical therapy or "other hocus pocus therapies like that." Wh-what? The last bit of strength I could muster was used to accomplish three things: First, to respond to his sardonic comment with, "Since when are these modalities hocus-pocus?", second, to procure an MRI order for what I believed was causing the pain (my uncooperative cervical spine) and third, to leave that office as fast as I could.

During the two weeks that I waited for the MRI and its results, John, my husband — an engineer (two for one!), got involved. Sometimes I jokingly call him "Dr. John" because of his intuitive ability to objectively figure out what's going on when others cannot. After hearing about this pain once again, while periodically checking in to watch my one-hour of respiratory treatments with four medicines, John suggested that possibly it was muscle strain from the many, many hours of treatments themselves. As I tried to juggle the nebulizer cup in one hand and reading, writing or typing with the other, John pointed out that I was tilting my neck, preferring the right side and, guess what?, straining the left side of my neck and shoulder in the process! Brilliant!

Now that we were fairly confident that the pain in my neck was due to muscle strain and not a person, place or neurologist, my husband suddenly disappeared and then reappeared like Superman (he said he would prefer an Ironman reference here) with a microphone stand. This particular microphone stand can be equipped with a spring clamp for receiving a mike. In the mike's place the PARI nebulizer cup fits well and securely within the spring clamp. At first we tried a small microphone stand that could be placed on the table. While that worked and reduced the strain on my body considerably, a longer floor stand worked even better because of its greater flexibility in adjustment and positioning.

> "Having the nebulizer cup held by the [microphone] stand has resulted in a relaxed jaw, unstrained neck, and straighter back while nebulizing."

Having the nebulizer cup held by the stand has resulted in a relaxed jaw, unstrained neck, and straighter back while nebulizing. Both hands are now free to relax, write, type or hold a book. Since the stand is adjustable to height and horizontal length, you can position it for maximum comfort. I have found that using it also reminds me to sit up straight. We often don't realize how much of an orthopedic surgeon's nightmare we might be if we continue to use poor posture while performing our hours of treatments.

Within days of using this "new device" which we like to call the "contraption" (with or without a Spanish accent), the pain had subsided considerably. As I often do, I didn't use the microphone stand one day to see if it really, really was the reason for improvement. And as often consequently occurs, I paid for that poor decision with the pain's return. After receiving the results from the neurologist, it came as no surprise when the MRI, EMG (electromyogram) and NCV (nerve conduction velocity) were all normal! Diagnosis: muscle strain. Brilliant, indeed.

I believe that as we age the poor posture that we may have exhibited from earlier years can catch up to us leading to more muscle strain and orthopedic issues. As anyone ages, new aches and pains often appear but because of our many hours of respiratory treatments, we, as CF patients, are particularly susceptible to experiencing other aches and pains unique to frequent, prolonged nebulizer use. A little self-observation and intervention (sit up straighter; find ways to relax your jaw, neck and shoulder; take yoga, stretch) can potentially go a long way in preventing these aches and pains that may crop up later.

Fortunately, the pain I was experiencing is now barely noticeable. I only feel a little occasional twinge that reminds me to continue using the nebulizer-on-the-mike-stand device (i.e., contraption) and to definitely make appointments soon for some of that "hocus-pocus" massage and physical therapy. And now that I have my own mike stand, maybe I will soon be ready for that talent show… ▲

Jeanie is 46 years old and a physician with CF. She lives with her husband and three teenagers in Los Angeles.

The Search for Modifiers of CF – The US CF Twin and Sibling Study

In late 2000, Garry Cutting, a geneticist at Johns Hopkins Medicine in Baltimore, gathered a research team together to discuss the feasibility of hunting for genes - other than CFTR - that alter the course of cystic fibrosis (CF). Dr. Cutting had been working in the field of CF genetics for the better part of 15 years, and has many publications reflecting his work. When the CF Gene was identified in 1989 (by a team of researchers in the US and Canada), CF families sounded a sigh of relief. At last, the basis for developing a cure for CF! Yet, despite Herculean efforts over a number of years, no one in 2001 was very close to finding a cure for the basic defect in the CFTR gene that causes CF.

Dr. Cutting and others in the field researched some of the biology of CFTR, how it works, and the consequences of certain CFTR mutations, but they puzzled about some of the CF families they had come to know so well. Why were there such stark differences in CF siblings' lung disease, and overall status, when they have the same parents, the same genotype, live in the same home, and generally go to the same schools? As he began to ponder the problem and review the publications of other colleagues, he began to realize that there must be other genes at work in the CF picture.

The CF Twin and Sibling Study began its long run as the CF Twin Study. In 2001, approximately 100 twins with CF were living across the US. With the support of the CF Foundation, the project goal was to recruit every twin pair with CF, gather information about their diagnosis, clinical course, growth, environment and pulmonary disease along with blood samples, to determine the "phenotype" (clinical picture) and the genotype (genetic code) that were associated with one another. Collecting a significant amount of clinical information, in the framework of a family based study, could ensure that identification of "phenotype" was done with compelling accuracy, and when "run" against a person's genetic makeup might point to a gene that caused or contributed to the "picture". Information about the environment could rule out – or in – certain things like secondhand smoke or inconsistent therapies as influences in overall severity.

> "Why were there such stark differences in CF siblings' lung disease, and overall status, when they have the same parents, the same genotype, live in the same home, and generally go to the same schools?"

In those early years, work on the Human Genome was incomplete. Many genes that contribute to disease hadn't been identified or weren't fully understood. Genes that were *thought* to contribute to disease (candidate genes) were proposed and studied based on how researchers knew- or thought- they worked. One gene for example, Mannose Binding Lectin, is involved in innate immunity thought to influence resistance or susceptibility to lung infections and survival. Another, TGFß 1, influences the development of fibrotic tissue; could it influence lung function and FEV1? These were the questions that the CF Twin Study Team set out to answer.

They rolled into a wall called local IRB review. In 2001, there were over 150 CF Care Centers, Adult Programs, and Affiliates across the US. Most of them required local review of this study, which slowed progress to a crawl. Local review could take anywhere from a few weeks to a year, and lent considerable difficulty to enrolling participants. Not to be deterred, the team offered assistance with paperwork as needed to any center in getting the project up and running in their clinics.

Surprisingly, there are still twins with CF living in the US who have not participated in this study - but the efforts to reach them continue. In the interim, the research team shifted its gears and began to think about siblings with CF. There were far more siblings than twins in the US, which could mean a greater ability to find gene differences that occurred rarely or had smaller effects on illness.

The same type of clinical and environmental data would be collected, along with the siblings' blood sample, but a new twist was added. The team would ask for the parents of CF siblings to participate with their children in the study by giving a blood sample as well. The transmission of parental genes to their children would be extremely informative as to what gene differences were "preferentially" passed on and

Continued on page 30

The Harlequin Wave of Pleasure and Pain

PHOTO BY MICHELLE COMPTON

Submersion is sweet comfort.
Nurse the pain with cool fresh liquid.
It's time to rest and heal.
But not for long, the future haunts me.

Ascension is abrasive and hostile.
Although battered and bruised, it's time to fight.
I don't belong here but there are things I must do.
Am I strong enough to get what I need?
It surrounds me but I can't have it.
Are others stabbed by this frustration?
I think not. Why did I bother to come?

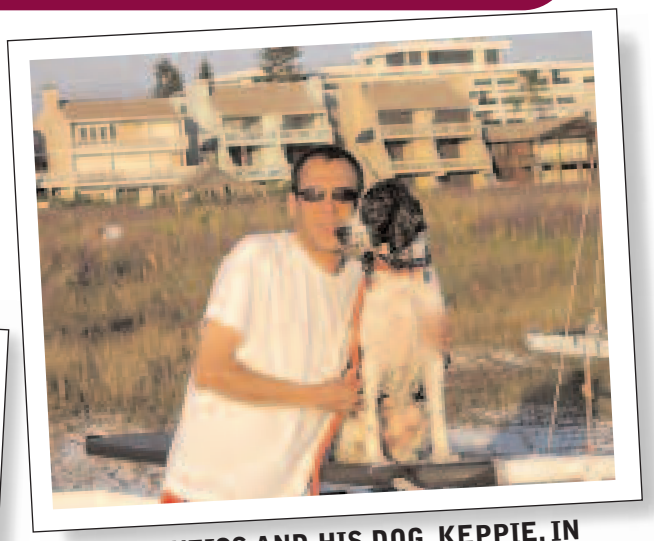
Submersion is sweet home.
It's better down here.
They know me here.
Is there a way to stay?
I can just stay and rest.
Forever rest.

– *Steve Peterson*

"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...



RICHARD WEISS AND HIS DOG, KEPPIE, IN SIESTA KEY, FLORIDA.

JERRY CAHILL TAKING IN THE VIEW OF THE HUDSON RIVER IN MANHATTAN.

LISA MARTINI AND KURT ROBINSON AT A FRIEND'S WEDDING THIS JUNE.

ISA STENZEL BYRNES (L) AND ANA STENZEL (R) HELP RICH DENAGEL (C) CELEBRATE HIS 40TH BIRTHDAY IN SAN FRANCISCO.

KATHY RUSSELL AT HER DESK.

BOOK REVIEW

Sick Girl Speaks: Lessons and Ponderings Along the Road to Acceptance

By Tiffany Christensen

Reviewed by Katrina Bischoff-Howell

"Sick Girl Speaks" is an interesting and informative patient advocate book written by a young woman who has cystic fibrosis (CF) and survived two bilateral lung transplants. Tiffany Christensen uses her own wit and wisdom relating her personal experiences of navigating through the medical system and general life issues relating to disability. Throughout the book she also shares her spiritual views and how she has integrated them into her life.

I find especially intriguing her chapter on pain and cell memory and how the body remembers certain procedures and tests and how one's body can have a kind of delayed emotional reaction that can come out of the blue. This particular experience happened while she was playing a game. *It was almost as if I could remember being in the transplant position for seven hours; my hands locked above my head and my ankles strapped down. There was a part of me somewhere that remembered the discomfort of this and how desperately I had wanted to move away from the hands and the tools invading my insides. I sobbed for a solid hour and let my cells release the pain of my two surgeries. (p.41)*

Tiffany also discusses how important it is to know one's own physical limitations and not overwhelm oneself with too many social commitments, work-related tasks or everyday things one normally would have at home. Many, but not all, people without health concerns don't worry about getting short of breath doing household chores, taking a shower and dressing for the day. The author suggests pacing oneself. *When you become ill, the body no longer has the same level of energy it once did. I could feel the energy being drained from me doing ordinary tasks. I called this energy reserve my gas tank and clearly visualize when it was full (rarely!), when it was being drained (and by how much) and when it was empty (often!). Like the life regeneration you'll find in a common video game, it takes a time of stillness and quiet to refill the gas tank. It became essential for me to integrate these times of regeneration into my daily routine. (p. 82)*

As a patient, as well as a caregiver to my husband who is a bilateral lung transplant recipient, I can relate to many of the life challenges that Tiffany has faced. I also appreciate how comforting it is to know that someone else is out there who has gone through life experiences similar to my own. I have seen both sides of the coin, so to speak, being a patient and a caregiver. I think she sums it up best with the following statement. *When you're sick, it's very easy to fall into the pattern of constantly focusing on yourself and your current state. Being a caregiver is a very stressful and sometimes horrible position to be in. Remember to be aware that your caregivers have difficulties too. Remember they can burn out and need some balance, a.k.a. get away from you. Don't forget to look outside yourself and see all that they do for you, then share your gratitude. (p. 149)*

In short, I would recommend this book to parents, loved ones and people who are newly diagnosed with CF or another disability. The questions and answers in the back of the book are particularly helpful to those patients interacting with their physicians and CF team. It is perfect for young teens becoming more self sufficient. It is also a good review for those of us who have been through similar medical procedures, tests or circumstances. I admire Tiffany's candor when interacting with her specialists and physicians. It brings an authenticity to the doctor-patient relationship that sometimes doesn't get related in this genre. ▲

Katrina is 38 and has CF. She lives in Carlsbad, CA. with her 51-year-old husband, Philip, who had bilateral lung transplant in 2005.

Photos of Summer

By Pammie Post

A Few years ago, my adoring older brother lent me his digital Nikon SLR. It didn't take long for me to be hooked on photography again, having given it up back in 1983. Photography has become a passion and a healing art. This hobby has carried me through many medical journeys, especially last year with chemo treatments.

Macro (close up) photography is my favorite, closely followed by landscape. I always have relished the little things in life. With macro, my ambitions are to help others become more aware of the beauty surrounding them. I look forward to the coming autumn season.

"Ladybug on Milkweed", New Canaan, CT

Following a hospitalization, I was on a mission to find and photograph a ladybug for a doctor as a thank you for all her help. She always wore something with a ladybug. Macro photography is a favorite because it enables me to focus in on details and perhaps share the beauty, form, function, color, texture, etc. with others. The small things in life do make a difference. Take the ladybug, or more accurately, lady bird beetle; they are a gardeners' best friend - a biological pest control. They consume many "bad" bugs.

"Cadence Racing towards the Leeward Mark", South Norwalk, CT

Photography is about light. Early morning and late afternoon light are two of my favorite times of day to shoot. Our small Yacht Club has a Wednesday night racing series. Racers from Stamford join our club. Races take place on Long Island Sound off the Norwalk Islands. Spinnaker and non-spinnaker classes participate. My husband and I were in our boat below the leeward mark. I wanted to get the backlight from the setting sun, to have the light shine through the sails and silhouettes of the crew. Cadence, owned by great friends and terrific racers, was well ahead of the pack. I love to photograph for our club's newsletters and be able to document events.

"Unfurled", Blue Lotus, Wave Hill Gardens, Bronx, NY

Water lilies happen to be one of my favorite plants. Could be because I love anything to do with water, be it watching waves or being in boats going through waves. Wave Hill Gardens is located on the Hudson, not far from NYC. It's a gem of a place, a public garden, plus they had water lilies in bloom. "Unfurled" was the title for a Garden Club photo contest. The Zone II annual Gardens Clubs' Flower Show was called "Harbor lights". I chose this shot for "Unfurled" because it had water. My Blue Lotus was voted by our Garden Club's members to represent the Zone II Gardens Clubs' photography class and won first prize.

Pammie Post is 54 and has CF. She had bilateral lung transplant on October 10, 2000. She is a former Director of USACFA. She and her husband, Bill, live in New Canaan, CT.

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.

Information from the Internet...

Compiled By Laura Tillman

This issue brings a potpourri of articles from the Internet

CFRD

Glargine versus NPH insulin in cystic fibrosis related diabetes. Patricia Grover, William Thomas and Antoinette Moran. Journal of Cystic Fibrosis. Volume 7, Issue 2, March 2008, Pages 134-136

Cystic fibrosis related diabetes (CFRD) with fasting hyperglycemia is found in 15% of adult and 11% of adolescent CF patients. Because of concerns about hypoglycemia, it is not common practice to treat CFRD with 24-hour basal insulin therapy, despite evidence that insulin deficiency may contribute to protein catabolism and have an adverse effect on weight, muscle mass, pulmonary function, and, ultimately, survival. We hypothesized that insulin glargine would improve blood glucose control and weight in patients with CFRD without causing hypoglycemia. A randomized cross-over study compared 12 weeks each of bedtime NPH or glargine in 19 CFRD patients. There was significantly greater reduction in fasting plasma glucose with glargine , and participants showed a non-significant trend towards weight gain with this insulin. No serious hypoglycemia occurred. A study of longer duration is needed to determine whether insulin glargine impacts protein catabolism and overall clinical status in CF patients, but these initial data suggest that this is a promising therapy in CFRD.

http://www.sciencedirect.com/science?_ob=ArticleURL&_udi=B6X2D-4PCR1S3-1&_user=10&_coverDate=03%2F31%2F2008&_rdoc=7&_fmt=summary&_orig=browse&_srch=doc-info(%23toc%237268%232008%23999929997%23683000%23FLA%23display%23Volume)&_cdi=7268&_sort=d&_docanchor=&_ct=14&_acct=C000050221&_version=1&_urlVersion=0&_userid=10&md5=bf6d6f7332a8bfc5c711112f52180696

Continuous Glucose Monitoring in Cystic Fibrosis Patients According to the Glucose Tolerance. F. Moreau, M. A. Weiller, V. Rosner, L. Weiss, M. Hasselmann, M. Pinget, R. Kessler, L. Kessler. Horm Metab Res 2008

Cystic fibrosis (CF) is associated with a long preclinical state of abnormal glucose tolerance. The aim of this study was (i) to evaluate the profile of glucose tolerance in young adults with CF and (ii) to compare these results with those obtained by a continuous subcutaneous glucose monitoring (CGMS). CF subjects with fasting glycemia inferior to 126 mg/dl were included in the study. An oral glucose tolerance test (OGTT) identified the subjects either with a normal glucose tolerance (NGT), or impaired glucose tolerance (IGT), or diabetes. CGMS revealed pathological glucose excursions not only in patients with impaired glucose tolerance at OGTT but also in patients with a normal glycemic profile. CGMS could be a useful tool for the early detection of hyperglycemia in patients with CF.

Continued on page 23

Internal Happiness and External Smiles

By Kurt Robinson

KURT ROBINSON AND LISA MARTINI SPENDING THEIR FIRST WEEKEND TRIP TOGETHER IN NEWPORT, OREGON.

I strongly believe that happiness plays a key role in anyone's health, particularly in those of us with CF. As we all know, CF can deal us some pretty hard blows, at times, that can take a while to recover from, if ever. Julie Desch talked about being happy and enjoying life in the Winter 2008 issue of *CF Roundtable,* but recently it hit home for me.

In general, I'm a happy person. I try to look at the positives and do my best to make the most of each day. It would be easy to dwell on the negatives associated with CF, so rather than waste my life doing so, I choose to focus on what makes me happy. While I could (and someday just may) write an entire novel on my life and how fortunate I have been, I only have room for the condensed, yet important version. I have realized that my happiness has, until recently, been able to be summed up into three main categories, about all of which I have written in past issues: my family (particularly my niece and nephew), my friends, and sports. All three provide me with absolute happiness.

You can now add a fourth to that list: my girlfriend. Looking ahead, I see that the Focus topic for the Winter 2009 issue deals with relationships, and I will probably expand on it more in that issue, but this is something too important to wait. This issue's Focus topic deals with our equipment. I believe that you can expand equipment to include your "internal equipment". By internal equipment I mean your happiness, state of mind, and mental health. If we don't take care of our internal equipment properly and pay enough attention to it, then it makes it that much more difficult for our external equipment to be used to the best of its ability.

I had been single for about five years. I knew that I wasn't the type who wanted to date a lot of different women. Instead, I chose to stay single, enjoy life, and wait until that special person came around. I figured that I had waited 24 years, so if I had to wait another 24 years or longer, it would be worth it.

Luckily, I didn't have to wait that long because Lisa came into my life. Funny thing is, neither one of us was looking for a relationship at the time. There were passing thoughts that it would be nice to be in a relationship, but this past May was such a busy month for me that I didn't put any stress on myself for not being in one. I recently had been promoted at work, was chairperson for the Cystic Fibrosis Foundation's GREAT STRIDES fundraiser where I live, and was able to see Alan Jackson, one of my favorite musicians, in concert. So, all in all, you could say I was extremely happy with how my life was going. Lisa had just gotten out of a long-term relationship, and leading a busy life like I do, she wasn't looking either.

On May 9, my life became a lot happier and my internal equipment began working better than it has in a while. We hit it off instantly and knew there was something more than a "just friends" connection. When we finally made our relationship "official", it took my family and friends by surprise (as well as both of us to some degree), but in a good way. I began thinking about everything I wanted to do in life and everywhere I wanted to go—and they all included Lisa joining me. Little did I know that she felt the same way. I wanted to introduce her to my family and friends. I wanted to share my life with her—and a big part of my life obviously involved CF. However, I felt so comfortable around her and when I told her about having CF and what my daily life is like, she was genuinely interested and was not taken aback or didn't seem surprised about what I had to say.

I always try to stay on top of my health, but this was just the boost that I needed. I began working out more, getting more sleep at night, making even more of a point to stay on top of my medications and therapies. I realize that I have found someone who is so supportive and wants

to do whatever she can to keep me healthy. Lisa is always so patient and never minds having to wait the 20-30 minutes for me to do my breathing treatments and is always looking out for my health. Wanting to become a sports nutritionist in the future, she is fascinated (and a bit jealous) of my diet and is interested in what all of my medications do. Having support from those with whom you surround yourself is vital in keeping your internal equipment up and running. The smallest things can make a big difference, even if we don't realize it.

As I said earlier, I've always been a happy person, but even my family and friends have noticed a difference. I smile and laugh even more, wake up even happier, take more pictures (I'm a big picture person!), and think about the future more than ever before. Just the other night I began to make a "bucket list", so to speak, of everything I want to do in life. I prefer to refer to it as a "fun list", rather than a "bucket list". It's safe to say that I savor and cherish life to the fullest. I no longer think as often about the decline I have had in my lungs within the past ten years, but rather what I can do to get my lungs healthier. It's because I want to enjoy the future and you can believe this means finding a cure for CF and living a life without CF. It also includes making memories, taking trips, and trying new things—all with Lisa.

Lisa's inner self is as gorgeous as her physical looks. She's such a positive person, all the while managing to keep a very full plate: academics (she's a smart cookie!), volleyball (she rocks!), work, and spending time with her family and friends. As I always tell her, "Squeeze me in when you can." We both want the same for each other: for the other to be completely happy. For the first time ever, I can say that I am completely happy. All the pieces have fallen into place.

My internal equipment is working better than ever. I want to be able to go play volleyball with her, throw a Frisbee, go for a walk on the beach, or go on a hike. All of these things require my lungs and health, both mental and physical, to be in good condition. This summer promises to be another packed-full and busy one full of weddings, birthdays (my 25th and my nephew's 3rd), and adventures. I don't want to have any bumps in the road that will prevent me from enjoying it. But I also know that if a blip on the radar pops up, I will have the support of those around me—including Lisa. It is during those times, when my physical health may not be at its peak, that I have comfort in knowing that I don't have to worry about my internal equipment functioning improperly.

Take care and keep smiling! ▲

Kurt is 25 and has CF. He is a Director of USACFA. His contact information is on page 2.

Mailbox

Thank you so much for creating this amazing resource for CF patients. I am blown away by the quality of production and content!!!

Thank you.

Tiffany Christensen
Chapel Hill, NC

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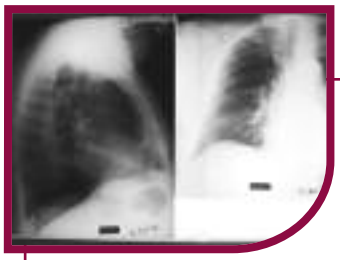


A DEEP BREATH IN
Getting Listed – Part 1

By Debbie Ajini

As I have mentioned recently, I am going to Pittsburgh for a lung transplant evaluation. Actually, by the time you read this, I already will have been there and back and received their decision. I plan on sharing that in the next issue. But now I want to share my story on how I got to this point.

While I had some hard struggles off and on during my childhood and adolescence, including culturing for B. cepacia in 1985, I did hold pretty stable once I was in my late 20s. I got sick in October 2004, while on vacation in Mexico. Over the course of the next four months my PFTs went from around 65% to 35% and lower. I thought for sure my doctor was going to start throwing around the idea of transplant. When we talked about it in February of 2005, she really felt I was just going through a rough patch. We decided together that I would just try to focus on doing everything I could to get out of this slump. I did start to make some progress, but then in June, I had a major episode of hemoptysis. That was when I really thought transplant might be on my short list. Again, my doctor suggested we wait and see what happened in the next few months. *DISCLAIMER: I must stress how this advice was the right advice only for ME and no one else. All people with CF need to sit down with their doctors and make the choices they feel are best for their own unique situations.*

After the hemoptysis, amazingly enough, I did begin to stabilize. While my PFTs didn't really change, I did go longer and longer without IVs, I was able to do more exercise and I also began to identify what things made me feel better and worse. I discovered that, if I was already feeling short of breath, sugar or dairy probably would make it worse. I had been using O_2 pretty much 24/7. I couldn't do things I used to. But, I was feeling better and definitely remaining stable.

Periodically I asked about transplant, and my doc always said, "Not yet." But part of me wanted to start doing the legwork because, if I went through what I did in 2004, I would lose too much lung capacity and literally not be able to do the legwork needed. In early 2007 my doctor agreed to start asking around. The general consensus was nobody was doing B. cepacia transplants. The fact that I heard centers would *not* see me, gave me some major motivation. I do not like to be told "No", especially when it comes to my life. The way I see it, what it all boils down to is, if I am willing to go into that OR and accept the risks, why can't they?

In July 2007 my PFTs went down a couple of points. I was now at the 30% mark – that magical number most transplant centers recognize as the point to consider transplant. Again, we heard that NO ONE was doing B. cepacia; we got spooked. We figured this would take quite a bit more work than usual. After many phone calls by me and my doctor we learned that we had a few possibilities, but only a few. So off my records went to a few places. What I learned is that some centers don't like to come right out and say no. They just happen to lose my records, not once, not twice, but three times! I would have preferred a polite no. And if they did, indeed, lose my records so often, imagine what they would do with my lungs! I also learned some centers say "No" in such a way that it could really take the wind out of my sails, if I let it. (I didn't!)

Finally we heard about Pittsburgh. I had two friends, also with B. cepacia, get evaluations scheduled. That was exciting and scary. I am so glad that there is a possibility someone will transplant me when I need it. And I am scared, too. For me, it means at some point I will have to do it and take that leap.

Now, I am just eager to get there and see what they have to say. My PFTs actually have gone up a percent or two and I have been off IVs 17 months. But that darn B. cepacia keeps whispering over my shoulder. This has definitely been a huge balancing act. Deciding to have a transplant or not wasn't so hard. It is the "When" that is a challenge. Many doctors, and people with CF, will tell you that there seems to be a magical window of the best time to do a transplant. There is a place between being too sick and too healthy, and it is different for every single person with CF. I do not know if I am in that window.

But, I do know I am ready for this evaluation. And I am ready for what they have to say. I am looking forward to being able to have something to formulate a plan around. If they say I am listed and at the top, then so be it. I do know how lucky I am to have this chance. If they say I am listed but not near the top, I know I can really start to step up my pulmonary rehab and some other things in my life to help keep me at the bottom as long as possible. If they say I am not ready to be listed, then I know to be thankful. If they say I am not a good candidate… well, I guess that would be a different column for another issue.

So for now, I am ready. I have done what I can to get ready for my evaluation. Look for my "Part 2" in the next issue! ▲

Debbie is 37 (38 on August 3) and has CF. She is a Director of USACFA. She and her husband, Louie, share their home with their yellow lab, Max. Her contact information is on page 2.

STENZEL *continued from page 7*

my body could handle no more.

For a very privileged few, at the end of our CF lives, our diseased lungs are replaced with healthy lungs, redeeming our suffering for a chance at health. This July, I will be competing in the US Transplant Games, along with other CF adults like Andrea Eisenman and Paul Feld. We will witness another wondrous miracle of the body: that a dead person's lungs can breathe for us. Again, I'm in awe of the body! Of course, before I compete, I will have to ask, "How are my sugars? How's my hydration? Sunscreen?" I'm likely to feel frustrated that my body is so high maintenance. Something may come up, limiting my goals, and I'll just have to deal with my body where it is — and I know that won't be easy. But, hopefully, when I'm competing, totally breathless and every ounce of my muscle burning, I will feel tremendous gratitude for my body.

By recognizing the strengths of the CF body, I'm on the right path toward body acceptance. Earlier in this essay, I shared the goal of becoming friends with my body. A true friend listens, supports and offers encouraging words in both good and bad times. That's how I am determined to act toward my body. As its friend, I start by having conversations with my body, I get to know it and pay attention to its cues. I see its strengths, I forgive its weaknesses, and I am flexible with whatever comes up. It is ok to be mad at it, or to give it a hug. We've come a long way, my body and I. I don't know where this body will take me in the future, but I am in store for an amazing friendship. ▲

Isabel Stenzel Byrnes is 36 and has CF. She is a co-author of "The Power of Two: A Twin Triumph over Cystic Fibrosis". She and Andrew live in Redwood City, CA. She invites spiritual writers to share their 'spirit medicine'.

TILLMAN *continued from page 19*

http://www.thieme-connect.de/ejournals/abstract/hmr/doi/10.1055/s-2008-1062723

NEWS RELEASES

PTC Therapeutics Announces Data Supporting Cough Frequency As A New Outcome Measure In Evaluating Treatments For Cystic Fibrosis. Findings Show Cystic Fibrosis Patients Cough More Than 600 Times Per Day.

PTC Therapeutics, Inc. (PTC) today announced new data suggesting that the quantification of cough frequency may offer a clinically meaningful outcome measure in cystic fibrosis (CF). Cough is one of the most prominent and burdensome disease-related symptoms in CF. According to data, patients with CF cough a remarkable 324 to 1,569 times per day, with an average of 643 coughs per day. In comparison, healthy individuals generally cough fewer than 16 times in an entire day. "Cough is one of the major symptomatic manifestations of the underlying disease process in CF," stated Eitan Kerem, M.D., head of the Department of Pediatrics and Cystic Fibrosis Center, Hadassah University Hospital. "Chronic excessive coughing is a burden on CF patients and a source of anxiety for caregivers and loved ones. Frequent and intense coughing has a profound effect on the overall quality of life of the patient – compromising work, school, sleep and social interactions." The study was designed to assess cough frequency as a measure of clinical benefit.

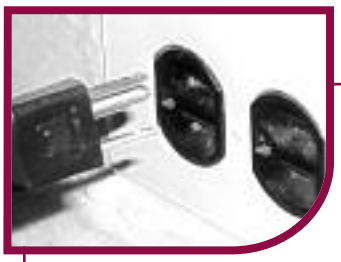
PTC Therapeutics Announces Data From Additional Clinical Studies of PTC124 in Cystic Fibrosis Confirming Activity

PTC124 is an orally delivered investigational new drug for the treatment of genetic disorders due to nonsense mutations. Nonsense mutations are single-point alterations in the genetic code that prematurely stop the translation process, preventing production of a functional protein. In Phase 2a clinical trials in nonsense-mutation-mediated cystic fibrosis (CF) and in nonsense-mutation mediated Duchenne muscular dystrophy (DMD), PTC124 has demonstrated the ability to produce functional protein across a variety of nonsense mutation types. Across all clinical studies to date, PTC124 has been generally well tolerated and has achieved target plasma concentrations that have been associated with activity in preclinical models. PTC124 is currently in Phase 2b development with the goal of demonstrating that increasing functional protein levels in patients with nonsense-mediated genetic disorders may provide clinical benefits.

Foundation and Vertex Announce Positive Early Results for VX-770

The Cystic Fibrosis Foundation and Vertex Pharmaceuticals announced today that VX-770, an oral drug in development that targets a basic defect in CF, showed promising results in an ongoing Phase 2a clinical trial for patients who carry the G551D mutation of CF. The drug is being developed by Vertex Pharmaceuticals Incorporated. Patients who took the drug for 14 days showed significant improvements in several key indicators of cystic fibrosis, including lung function, nasal potential difference measurements and sweat chloride levels. The findings suggest that VX-770 improves function of what is known as the faulty CFTR protein. This early data is promising and

Continued on page 27



UNPLUGGED...
With Jerry Cahill

By Richard De Nagel

Welcome back to another edition of "Unplugged". I cannot believe how fast time flies! 2008 is almost half over. I am not one who's particularly into New Year's resolutions, but I do wonder what I've accomplished so far this year. Have I taken care of myself? Am I feeling good about myself and the decisions I've made? How are things with me and CF? I find that the more aware I am of how I'm feeling, especially in regard to CF, the better I take care of myself. Sometimes I hate having CF and dealing with nebs, the Vest®, etc., and when I am in that head space there's no doubt I don't take care of myself the way that I should.

Now on to more exciting things, like our latest interview subject: Jerry Cahill. Simply put, Jerry rocks. He is a no-nonsense guy, and a man of few words who is right on target with CF and himself. Jerry has a lot going on, and is doing great work that gives back to our community. And he has a great outlook on CF too. It is a part of his life, not his life.

So, here's Jerry.

1) Name? Jerry Cahill

2) Age?

52 and Living Breathing Succeeding with CF.

3) Where do you live, and does that have any effect on your health?

Brooklyn, NY, but I've also lived in Kansas City, KS, and Connecticut. And they did not have any effect on my health that I was aware of.

4) When were you diagnosed with CF?

At 11 years of age.

5) Who is your doctor? Hospital? Do you like him/her?

I have a whole "team" of doctors at NY Presbyterian and UNC - Chapel Hill. CF doctor - Dr. Emily DiMango and Dr. Mike Knowles; adult pulmonologist - Dr. Larry Schulman; Transplant Team - Dr. Selim Arcasoy and Dr. Josh Sonett; and ENT - Dr. Hector Rodriguez.

JERRY CAHILL

6) How would you describe your health now?

Stable.

7) What type of chest physical therapy do you do? Are you compliant with it?

I tried them all - regular chest PT, The Vest®, Flutter®, and Electro Flo 5000® percussor along with lots of exercise (jogging, biking, weight lifting and some swimming). I personally find that exercise, the percussor and the $35 Flutter are the best!!

8) What was your 'welcome to the world of CF moment?' (When you began to realize what CF is?)

My first hospitalization for IV antibiotics was at the age of 21, when I started in the working world and stopped exercising every day. Being in the hospital was like being in a prison - not that I have been in prison, but I felt like a "caged animal".

9) What is the newest/favorite music in your iPod/CD player?

Viva la Vida by Coldplay

10) Are you working? How is that going?

Stopped working four years ago due to the progression of CF but currently volunteer a few hours/week at the Boomer Esiason Foundation.

11) Do you believe in a Higher Power? Are you religious?

Yes, a little bit.

12) What are your hobbies? Does CF interfere?

Track and field, pole vaulting and biking.

13) What is your relationship status? Happy about that? Does CF interfere?

Single - married to the sport of track and field and coaching pole vaulters. I have 15 kids, whom I coach.

14) What is your most embarrassing CF moment?

Getting a sperm count test.

15) What gets you through the tough days?

Being disciplined and knowing that things will get better.

16) What do you hate most about CF?

High maintenance - a lot of therapies.

17) What is your favorite movie? TV show? Why?

Forest Gump - a good mix of life experience, and House - love the

JERRY CAHILL VAULTING 12'0 IN THE NEW JERSEY OUTDOOR CHAMPIONSHIPS OF MASTERS ON JUNE 14, 2008. HE TOOK FIRST PLACE FOR HIS AGE GROUP.

arrogance.

18) Do you have kids? Want them?

No. No.

19) What do you look forward to?

Every day.

20) Do you think having CF is a good thing or a bad thing?

It is what it is.

21) Tell us about your friends?

Athletic, competitive, good people.

22) What is your favorite color?

Blue.

23) Do you spend time with other people who have CF? If so, what do you do together, and how important is this to you?

No, just talk on phone a lot as a volunteer at the Boomer Esiason Foundation. Also sometimes do podcasts, but will wear a mask.

24) Do you spend time educating yourself about CF? How important is this to you? What effect does this have on your treatments, rapport with your doctors, self-image?

Sometime, but I am not absorbed in the world of CF. I have CF, but it does not rule my life and I do not obsess about it.

25) Are you a morning, afternoon, evening or night person?

All the above!

So that is Jerry! He has such a level head and a sensible approach to his life. And don't we all have a team of doctors? And haven't we all tried every type of Chest PT? I think what CF is to me may not be CF to someone else. For me, CF is pulmonary illness, a sinus condition, GI problems and an emotional disease. No matter how hard I try not to, I have feelings about my CF everyday. Have you ever counted the number of times a day you thought about CF? It always is there. And for me, it's emotional. Some of the time I don't know what I am feeling, but I can figure it out through my actions; if I'm rebellious or angry. If I don't care, I'm depressed or sad. The more in touch I am with what is going on with me the better care I take of myself. However, awareness of my emotions does not always translate into compliance. Compliance is the difficult goal, and dealing with what is going on inside my head and heart helps me reach that goal.

I was at a CF conference out here in San Francisco recently, exploring the idea of transitions. Remember when you left your pediatric clinic and moved on to an adult clinic? It is not just the adult clinic you move to; it's the adult hospital, the adult floor, the adult staff, the adult perspective on our disease. I imagine it was more difficult than I care to remember, though I do remember the fear. I have that same feeling every time I move to a new clinic. It's also an opportunity to get in touch with all the fears I have associated with my CF, such as thoughts about how long I have left, if I'm getting sick, or if I'm backed up again. Once I acknowledge the fear, though, it's undoubtedly easier to deal with. Thankfully, while it's still with me, all of my emotional baggage has gotten a little lighter as I get older and wiser. I am wiser, right? I'm definitely not as fearful as I once was, not as angry and much more compliant. Getting here has been a long and challenging process, and it's a process that will continue until I'm an old man. It's a good place to be.

Lastly, for the next installment of "Unplugged" it would be great to interview someone in their late teens, twenties, or early thirties. I am tired of all the "old farts". So if you're interested or know someone who might be, shoot me an e-mail. Thanks.

Till next time... ▲

Rich turned 40 on July 5, 2008. He has CF and is a Director of USACFA. His contact information is on page 2

Richard Weiss: A Hero of Hope Living with CF

At 46, **Richard Weiss** is determined to take the best possible care of himself, while living a full and happy life. His positive attitude serves as an inspiration to other people with CF. Based on most recent CF data, the median life expectancy for someone with CF is 37 years old.

Richard and his family have a special place in the CF community since Richard unknowingly coined the nickname "65 Roses" for cystic fibrosis, when he was 4 years old. Richard's mother volunteered to work with the Cystic Fibrosis Foundation soliciting donations when she discovered that all her sons were diagnosed with CF. One day, unbeknownst to her, her young son Richard overheard one of her phone calls and he told his mother that he knew she was working for "65 Roses". The phrase caught on and now children with CF sometimes refer to their disease as "65 Roses" because it is easier to pronounce. Richard's nickname for CF inspired the symbol of a rose that now represents the Cystic Fibrosis Foundation.

Richard knows that one of the keys to being healthy with CF is staying compliant to his medical routine. He enjoys going to the gym and knows that his medical routine is incredibly important to staying well. Richard describes adherence to his medical regimen as "staying to the cause."

Richard can truly speak to the idea of maintaining balance with cystic fibrosis. In addition to spending time with his family and working at a volunteer canine rescue organization, Richard participates in numerous volunteer activities in the CF community, such as serving as a speaker at fundraiser events. With his commitment to his health, positive attitude and perseverance, Richard inspires everyone around him.

Calling All Writers

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

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

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

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

USACFA
PO Box 1618
Gresham, OR 97030-0519.

could have important implications for studies of other drugs in development. This is the first time that any potential therapy has improved the abnormal sweat chloride (salt) levels in a person with CF. Excessive sweat chloride is a key clinical indicator of cystic fibrosis.

FYI

A single centre experience of liver disease in adults with cystic fibrosis 1995–2006. K.L. Nash, M.E. Allison, D. McKeon, D.J. Lomas, C.S. Haworth, D. Bilton and Graeme J.M. Alexander. Journal of Cystic Fibrosis Volume 7, Issue 3, May 2008, Pages 252-257

Liver disease was common in adults with CF but disease progression was rare. Thus liver disease detected and closely monitored in adults appeared to have a milder course than childhood CF. Splenomegaly, unrelated to portal hypertension may be a consequence of CF.

http://www.sciencedirect.com/science?_ob=ArticleURL&_udi=B6X2D-4R71KJV-1&_user=10&_coverDate=05%2F31%2F2008&_rdoc=10&_fmt=high&_orig=browse&_srch=docinfo(%23toc%237268%232008%23999929996%23689796%23FLA%23display%23Volume)&_cdi=7268&_sort=d&_docanchor=&_ct=12&_acct=C000050221&_version=1&_urlVersion=0&_userid=10&md5=c9e66aa143b77cd3d82d83d7f89f563a

Compliance in cystic fibrosis: An examination of infection control guidelines. Tracy Masterson, PhD, Beth G. Wildman, PhD, Benjamin Newberry, PhD, Gregory Omlor, MD, Elizabeth Bryson, RN, MSN, CPNP, CNS, Ann Kukay, RN. Pediatr Pulmonol. 2008; 43:435-442

The goal of this research was to begin the process of evaluating acceptability of infection control (IC) recommendations to CF patients and their families, determine whether compliance with IC guidelines differs from compliance with traditional CF medical treatment with respect to the variables predictive of compliance, and assess which patients are most likely to comply with IC recommendations. Participants were recruited during routine outpatient visits at a regional CF center located in a pediatric hospital. The sample included 44 child and adolescent patients, aged 9-18 years and their guardian, and 27 adult patients. All patients completed questionnaires and interviews. Results of this preliminary study suggest that many individuals with CF are unaware of or unconcerned with the risks involved in infection transmission via social contact with other CF patients. Further, most participants reported that they could benefit from friendships with other CF patients. Health belief variables were found to be predictive of compliance with both IC guidelines and traditional medical treatments in the adult and parent sample, but not in the child sample. Possible explanations for study findings are discussed and recommendations for future research on IC compliance are highlighted.

http://www3.interscience.wiley.com/cgi-bin/abstract/117946320/ABSTRACT

A Case Control Study Of Acute Renal Failure In Cystic Fibrosis Patients In The United Kingdom. Alan Smyth, Sarah Lewis, Carol Bertenshaw, Imti Choonara, Jean McGaw and Alan Watson. Thorax. Published Online First: 1 February 2008

There has been a recent increase in the number of reported cases of acute renal failure (ARF) in cystic fibrosis (CF). We conducted a case control study to determine the factors which are associated with an increased risk of ARF. In CF patients, the use of an intravenous aminoglycoside is a risk factor for ARF and gentamicin is more nephrotoxic than tobramycin. The majority of patients who develop ARF have a risk factor which necessitates withholding aminoglycosides or more closely monitoring their use.

http://thorax.bmj.com/cgi/content/abstract/thx.2007.088757v1

Consensus on the use and interpretation of cystic fibrosis mutation analysis in clinical practice. C. Castellani, H. Cuppens, M. Macek Jr., J.J. Cassiman, E. Kerem, P. Durie, E. Tullis, B.M. Assael, C. Bombieri, A. Brown, T. Casals, M. Claustres, G.R. Cutting, E. Dequeker, J. Dodge, I. Doull, P. Farrell, C. Ferec, E. Girodon, M. Johannesson, B. Kerem, M. Knowles, A. Munck, P.F. Pignatti, D. Radojkovic, P. Rizzotti, M. Schwarz, M. Stuhrmann, M. Tzetis, J. Zielenski and J.S. Elborn. Journal of Cystic Fibrosis Volume 7, Issue 3, May 2008, Pages 179-196

Although the diagnosis of CF is usually straightforward, care needs to be exercised in the use and interpretation of genetic tests: genotype information is not the final arbiter of a clinical diagnosis of CF or CF transmembrane conductance regulator (CFTR) protein related disorders. The diagnosis of these conditions is primarily based on the clinical presentation, and is supported by evaluation of CFTR function (sweat testing, nasal potential difference) and genetic analysis. None of these features are sufficient on their own to make a diagnosis of CF or CFTR-related disorders. Broad genotype/phenotype associations are useful in epidemiological studies, but CFTR genotype does not accurately predict individual outcome. The use of CFTR genotype for prediction of prognosis in people with CF at the time of their

Continued on page 28

diagnosis is not recommended.

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Zinc therapy for night blindness in cystic fibrosis. Christopher G. Tinley, Nicholas J. Withers, Christopher D. Sheldon, Anthony G. Quinn and Alan A. Jackson. Journal of Cystic Fibrosis. Article in Press

This is the first report of a supplemented CF patient presenting with clinical vitamin A deficiency to be successfully treated with zinc therapy alone. Therefore in addition to retinol supplementation, normalizing serum zinc levels may be important in maintaining the vitamin A status of CF patients. The interactions and synergistic effects between the two micronutrients are discussed.

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BACTERIA

The Streptococcus milleri group - An unrecognized cause of disease in cystic fibrosis: A case series and literature review. Michael D. Parkins, MD, Christopher D. Sibley, MSc, Michael G. Surette, PhD, Harvey R. Rabin, MD. Pediatr Pulmonol. 2008; 43:490-497

The Streptococcus milleri group (SMG) is increasingly recognized for their role in pyogenic infections including empyema and solid organ abscesses. However, SMG disease has rarely been identified in cystic fibrosis (CF). Inherent difficulties in both growing the organisms and distinguishing SMG from less virulent oropharyngeal viridans streptococci may have led to a decreased recognition of this as a CF pathogen. We report on six cases of SMG-related infection over a 4-year time-frame occurring within an adult CF clinic in Canada, and a further four cases identified through a literature review. SMG manifested disease as bronchopulmonary exacerbations in 7 of 10 patients, and 4 of 10 patients had extra-pulmonary dissemination of SMG infection. Noticeably, pulmonary exacerbations were frequently associated with atypically malodorous sputum. Furthermore, patients clinically responded to anti-microbial therapies with no anti-Pseudomonal activity. There was a consistent correlation of SMG disease and cocolonization with P. aeruginosa leading to speculation of polymicrobial interactions resulting in enhanced virulence. SMG deserves considerable attention as a potential pathogen within the airways of patients with CF.

http://www3.interscience.wiley.com/cgi-bin/abstract/117947196/ABSTRACT

Detection of Anaerobic Bacteria in High Numbers in Sputum from Patients with Cystic Fibrosis. Michael M. Tunney, Tyler R. Field, Thomas F. Moriarty, Sheila Patrick, Gerd Doering, Marianne S. Muhlebach, Matthew C. Wolfgang, Richard Boucher, Deirdre F. Gilpin, Andrew McDowell and J. Stuart Elborn. American Journal of Respiratory and Critical Care Medicine Vol 177. pp. 995-1001, (2008)

Pulmonary infection in cystic fibrosis (CF) is polymicrobial and it is possible that anaerobic bacteria, not detected by routine aerobic culture methods, reside within infected anaerobic airway mucus. Anaerobic species primarily within the genera Prevotella, Veillonella, Propionibacterium, and Actinomyces were isolated in high numbers from 42 of 66 (64%) sputum samples from adult patients with CF. Colonization with Pseudomonas aeruginosa significantly increased the likelihood that anaerobic bacteria would be present in the sputum. Species-dependent differences in the susceptibility of the anaerobes to antibiotics with known activity against anaerobes were apparent with all isolates susceptible to meropenem. A range of anaerobic species are present in large numbers in the lungs of patients with CF. If these anaerobic bacteria are contributing significantly to infection and inflammation in the CF lung, informed alterations to antibiotic treatment to target anaerobes, in addition to the primary infecting pathogens, may improve management.

http://ajrccm.atsjournals.org/cgi/content/abstract/177/9/995

TREATMENTS

Denufosol: A review of studies with inhaled P2Y2 agonists that led to Phase 3. Donald Kellerman, Andrea Rossi Mospan, Jean Engels, Amy Schaberg, JoAnn Gorden and Lynn Smiley. Pulmonary Pharmacology & Therapeutics, Article in Press

Among the most promising of the new therapies being developed for the treatment of Cystic Fibrosis (CF) are those targeted at increasing mucosal hydration on the surface of the airways. One of these therapies, P2Y2 receptor agonists, bypasses the defective CFTR chloride channel, and activates an alternative chloride channel.

This activation results in an increase in airway surface epithelial hydration, and through these actions and effects on cilia beat frequency, increases mucociliary clearance. The pharmacology of P2Y2 agonists has been confirmed in several preclinical and clinical studies. Denufosol tetrasodium is a novel second-generation, metabolically stable, selective P2Y2 receptor agonist currently in Phase 3 clinical development. It appears that high concentrations of denufosol can be achieved in the airways with very low systemic absorption. Denufosol has been generally well-tolerated in healthy volunteers and patients with CF. The most common adverse events were in the respiratory system, with cough having the highest frequency. Doses of 20–60 mg have been evaluated in Phase 2 trials of up to 28 days duration, and superiority relative to placebo on FEV_1 has been observed in patients with relatively normal lung function (FEV_1 greater than or equal to 75% of predicted). The first Phase 3 trial is a comparison of denufosol 60 mg and placebo in 350 patients with CF with FEV_1 at study entry greater than or equal to 75% of predicted.

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Antibiotic therapy against Pseudomonas aeruginosa in cystic fibrosis. Taccetti G, Campana S, Neri AS, Boni V, Festini F. J Chemother. 2008 Apr;20(2):166-9.

Antibiotic strategies against Pseudomonas aeruginosa infection in cystic fibrosis (CF) patients should consider the natural history of the P. aeruginosa infection, ranging from the first isolation of the germ in the airways to isolation at every microbiological culture, and the patient's clinical condition. Antibiotic treatment against P. aeruginosa given at the time of first isolation may prevent or delay chronic infection. The period of intermittent colonization can be considered the time before the development of mucoid P. aeruginosa phenotype. The optimal treatment strategy in this stage remains unclear in terms of agents used and duration of treatment. To treat acute exacerbation, the authors suggest using intravenous administration of two different classes of antibiotics. Maintenance antibiotics are administered to slow the decline in pulmonary function for P. aeruginosa chronic infection. The meaning of maintenance therapy has changed over time, beginning from intravenous quarterly anti-Pseudomonas antibiotics, irrespective of symptoms, to other strategies such as oral macrolides, ciprofloxacin or inhaled antibiotics (tobramycin and colistin). Aerosol delivery can provide a high concentration at the desired site with minimal absorption and therefore low risk of toxicity. There is scientific evidence that antibiotics are clinically effective in CF patients. Antibiotic selection should be based on periodic isolation and identification of pathogens and antimicrobial susceptibility.

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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.

TWIN STUDY *continued from page 14*

why they affected their child's fight with CF.

As this project has progressed, so has the understanding of genetic influences on CF. In parallel, the technology used to "hunt" for genes has exploded in capacity. What took researchers years to accomplish in the 1980s can be done in a few weeks in 2008. The detective work has been made easier with better tools, but the list of possible gene "culprits" has increased substantially.

One example is the investigation into the genetic modifiers of CF Related Diabetes. Through significant effort in enrolling patients, collecting correct and thorough clinical information, and employing several genetic analysis techniques, a modifier gene for CFRD has been identified. Diabetes risk was increased in study CF patients with a family history of type 2 diabetes. This suggested a role for type 2 diabetes susceptibility genes. A genetic variant in *TCF7L2* that is associated with type 2 diabetes in non-CF persons was associated with diabetes in CF in our family based study. This information is scheduled for publication in a scientific journal in the near future.

Thanks to the efforts of CF Centers and Families across the US, Australia, and Great Britain, we now have 2400 parents, twins and siblings participating in this project. The CF Twin and Sibling Study is grateful for the sponsorship of the National Institutes of Health and the Cystic Fibrosis Foundation. This journey began in 2001, and will continue through at least 2011. If you are interested in learning more about this unique project, please visit our website at: cftwinsibstudy.org or email the study team at: knaught1@jhmi.edu. ▲

Boomer Esiason Foundation CF Scholarship Program

The Boomer Esiason Foundation (BEF) is pleased to offer several different scholarship opportunities, available both annually and quarterly. In 2008, over $1,500,000 in scholarship money will be awarded.

Launched in 2003, the various scholarships are intended to assist people who have CF and are pursuing undergraduate and graduate degrees. The scholarships are awarded throughout the year and are based on a variety of factors, including: academic accomplishment, commitment to healthy living, and demonstrated financial need. The grants are made directly to the academic institutions to assist in covering the cost of tuition, and room and board.

One of the newest scholarships, from the University of Phoenix, presents an exciting opportunity to those with CF, who because of health limitations are unable to attend college physically, and have chosen to pursue an online degree. In 2008 the University of Phoenix is contributing 26 full-tuition scholarships to BEF for one degree program, each. University of Phoenix offers associate, bachelor, master, and doctorate programs.

BEF Scholarships are awarded quarterly with deadlines for applications on March 15, June 15, September 15 and December 15, 2008. The deadline for applying for the University of Phoenix scholarships was March 28, 2008. The Exercise for Life scholarship application deadline was June 27, 2008. The Bonnie Strangio scholarship applications were due by June 13, 2008. Applications for the Scholarship of the Arts were due by May 23, 2008.

Go to: www.cfscholarships.com for more information. Recipients of these scholarships all agree that it is easier to focus on academics and treatment, when finances are less of an issue. When you go to the BEF web site, you will find links to scholarships that are offered by some pharmaceutical companies.

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