CF Roundtable
A NEWSLETTER FOR ADULTS WHO HAVE CYSTIC FIBROSIS WINTER 2008

The 2007 North American CF Conference

By CF Roundtable staff

The 2007 North American CF Conference began in Anaheim, California, on October 4, 2007. More than 3,000 researchers, physicians and other CF professionals gathered from all over the world to discuss the latest developments in CF research.

The conference is comprised of plenary sessions each day. The plenary sessions are discussions of global topics that affect the work of most of the attendees and typically they last two hours. The other sessions during the conference mainly deal with ongoing CF scientific research and each lasts two hours. The idea behind the conference is to give researchers the opportunity to share their work and collaborate with others.

The spirit of collaboration is evident throughout the conference hall as small groups of attendees huddle together and discuss CF research or the care of people with CF. The conference is not for lay people and is specifically geared toward those working in either CF research or on the front lines of CF care. There are a limited number of sessions that deal with psycho-social issues. There are also small discussion groups where physicians can present case studies and gain insight and solutions from others. There were over 500 research posters that discussed CF research being done all over the world.

> "One project [Dr. Amaral] is working on involves a new class of potential CF therapies known as correctors, which seek to address the basic defect in CF."

The opening plenary address, "From Basic Science to the Clinic," was given by Dr. Margarida Amaral, a world-renowned researcher from Lisbon, Portugal. Dr. Amaral is an expert in protein movement through cells. She described one project she is working on that involves a new class of potential CF therapies known as correctors, which seek to address the basic defect in CF.

The conference attendees were also excited to learn about a presentation related to a new drug for the treatment of Pseudomonas aeruginosa infection in CF airways. The drug is nearing the end of the clinical trials process. Gilead Sciences announced the results of their Phase 3 AIR-CF1 trial of aztreonam lysine for inhalation (AZLI). The conference presentation showed that the Phase 3 trial demonstrated clear improvements in lung function and other clinical symptoms in volun-

Continued on page 30

INSIDE THIS ISSUE

CF ROUNDTABLE
FOUNDED 1990
Vol. XVIII, No. 1

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

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.

United States Adult Cystic Fibrosis Assn., Inc.
PO Box 1618
Gresham, OR 97030-0519
Voice mail or FAX (503) 669-3561
E-mail: cfroundtable@usacfa.org
www.cfroundtable.com

A WORD FROM THE PRESIDENT...

At Paul's request, this column was written by Cynthia Dunafon

You'll find many interesting perspectives on our Focus topic – "Positive Thinking' (PT), in this issue. **Paul Feld** demonstrates PT in his thorough (and sometimes harrowing) description of a lung collapse just shy of his third transplant anniversary. Look at **Kurt Robinson**'s article about the commitment required in PT – and its rewards. I also appreciate **Debbi Ajini**'s approach to PT: treating it like a therapy right alongside the others she does daily to maintain her health. We have a new voice this issue in **Heather Summerhayes Cariou,** whose two siblings with CF, Pam and Jeff, have given her the priceless legacy of never giving up. **Tiffany Christensen,** another new contributor, shares her experiences testing the limits of PT while facing her first lung transplant. My fellow mid-westerner and friend, **Janice Tate,** draws our attention to important points about PT: changing our thinking can change how we act, but we need faith to come to terms with our human limitations. **Meranda Honaker** shares her experiences in how to sustain hope.

Andrea Eisenman pays tribute to her dog, Sadie, who brought laughter, love, and companionship to her life during and after transplant. Be sure to read "Spirit Medicine" by **Isa Stenzel Byrnes,** which describes the lessons we learn by hiking in the dark – lessons of touch, smell, hearing, and courage. In "Wellness", **Dr. Julie Desch** describes how positive thinking changes our sense of time, when we focus our attention on particular moments/experiences. **Kathy Russell,** in "Speeding Past 50", draws our attention to the fact that PT can bring about disagreement and even conflict – for a while. That's where maturity comes into play, where handling time and handling people merge together.

If you haven't already heard of "The Power of Two: A Twin Triumph Over Cystic Fibrosis", turn to **Katrina Bischoff-Howell**'s review of this powerful autobiography. In "Unplugged", **Rich DeNagel** interviews **Mike Hyland,** a lung and kidney transplant recipient, former engineer and current pianist in three bands! **Nahara Mau** shares a lovely poem about listening, letters and life, while **David Lee** honors his donor family in "Black Licorice".

In "Ask the Attorney", **Beth Sufian** addresses whether an adult eligible for SSDI can extend those benefits to a dependent child, how to calculate the waiting period for SSDI benefits, and how to track your benefits application (or appeal) in a timely fashion. Check out the synopsis of the 2007 North American CF Conference and "News from the Internet" by **Laura Tillman** for updates on CF research,.

Dave Davison, who was diagnosed at age 32, lists useful advice for all of us who need to revisit the basics of responsible CF management, in his inaugural article "Awakening".

Happy New Year from all of us at the *CF Roundtable!* We wish you health and strength in 2008.

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

Ed Fleischman
Plainvieww, NY
66 on Deceember 24, 2007

Kristin McDonald
Pitt Meadows, BC, Canada
35 on December 14, 2007

Kristen Miller
Carencro, LA
27 on January 22, 2008

Ken O'Brien
Joliet, IL
45 on November 24, 2007

Susan Tumiel Smith
Williamsville, NY
52 on November 10, 2007

Laura Tillman
Northville, MI
60 on December 22, 2007

Heidi Reuter
Land O'Lakes, WI
21 on November 11, 2007

Jennifer Wilmoth
Federal Way, WA
35 on December 14, 2007

Marjorie Winoker
New Hyde Park, NY
55 on August 29, 2007

Wedding

Kristen & Bobby Miller
Carencro, LA
3 years on November 13, 2007

Marjorie & Daniel Winoker
New Hyde Park, NY
32 years on November 22, 2007

Transplant

Brenda Dorenfeld
Eldersburg, MD
Bilateral lung
4 years on October 7, 2007

Marjorie Winoker
New Hyde Park, NY
Bilateral lung
3 years on December 14, 2007

NEW BEGINNINGS

Education

Corey McElhone
Lubbock,TX
August 2007
Graduated from South Plains Association of Governments' Regional Law Enforcement Academy as a Basic Peace Officer

Engaged

Cynthia Dunafon & Steven Holloway
Chicago, IL
December 24, 2007
Wedding to be announced

Andrea Eisenman & Steve Downey
New York, NY
November 24, 2007
Wedding to be announced

LOOKING AHEAD

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

Winter (current) 2008: The Power of Positive Thinking

Spring (May) 2008: Traveling with CF (Submissions due March 15, 2008.) Do you travel? Have you found ways to make traveling easier? Have you found solutions to travel dilemmas? Please tell us your tips and ideas.

Summer (August) 2008: New Products and Equipment that Make Our Lives Easier (Submissions due June 15, 2008.) Have you found any new equipment that makes dealing with CF easier? What equipment do you like, and why do you like it? Tell us your ideas.

Autumn (November) 2008: Organ Transplants (Submissions due September 15, 2008.)

ASK THE ATTORNEY

Questions from Readers

By Beth Sufian, Esq.

The following questions are a compilation of questions asked by six different readers of *CF Roundtable*. Questions asked by readers are never disclosed without the agreement of the reader and information will never 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 the CF Legal Information Hotline at 1-800-622-0385. The Hotline provides free and confidential legal information to people with CF, their CF Center care teams and their families. The Hotline is sponsored by the CF Foundation, through a grant from Novartis. The Hotline also can be reached by e-mail at: CFlegal@cff.org.

1. I have CF. If I apply for Social Security Disability benefits will my child, who does not have CF, be eligible to receive a Social Security benefit?

A child who is under age 18 may be eligible for a monthly cash benefit from Social Security if his/her parent is deemed eligible for Social Security Disability (SSDI) benefits. Social Security will base the child's benefit amount on the amount the parent is receiving in SSDI benefits. The child does not receive the same benefit amount as the parent. A local Social Security (SSA) office should be able to calculate the benefit the child will receive if the parent is eligible for benefits. Typically, SSA provides an application for benefits for a child whose parent is receiving benefits, after the parent's application for benefits has been approved. Once the child turns 18 the child loses the cash benefit.

A child under age 18 will not be eligible for Medicare once the parent becomes eligible for Medicare. The child of a parent who receives SSDI will receive only a cash monthly benefit. If the family meets certain low income guidelines the child may be eligible for Medicaid, CHIP or insurance provided to children in the state where the child resides.

BETH SUFIAN

If the child of a parent who receives SSDI benefits meets SSA medical criteria himself before reaching the age of 22, that child may be able to continue receiving benefits based on the disabled parent's Social Security record. If the child turns 18 and meets Social Security's medical criteria the child could continue to receive a monthly benefit based on the parent's Social Security record. If the child is over 18 and meets the medical criteria, he would be eligible for Medicare 24 months after he turned 18. This is complicated. Please contact the CF Legal Information Hotline or SSA for further explanation if necessary.

2. I have been waiting for a decision on my Social Security application for over two months. How can I get my Social Security office to review my application quickly?

If you are applying for Social Security Disability Insurance benefits, the first five months you are unable to work is a "waiting period". This means that even if an application is approved, the applicant will never receive SSDI payments for the first five months the person was unable to work. Some Social Security offices do not rush to review initial applications for benefits because, even if the application is approved, the individual will not start receiving benefit checks until the applicant has been unable to work for five full months.

This means that if a person stops work on August 3rd, August will not be counted as a countable month. The person who stops work on August 3rd will have met the five months waiting period in February. Benefit checks will start in February.

If there are emergency circumstances, SSA is supposed to review an application quickly. This will help those who are applying for SSI benefits. SSI benefits start from the date of application, once the application is approved. There is no waiting period for SSI benefits. Therefore, an individual who has emergency circumstances and is applying for SSI should notify SSI of his circumstances. For example, if the individual is about to

> *"Often the denial of benefits is incorrect and after an appeal the individual is able to obtain benefits."*

lose his house and needs his benefit check to pay his rent or mortgage or risks becoming homeless.

Sometimes SSA loses files. If an application has been pending for more than two months, it may be a good idea to make sure that SSA has received the application for benefits and that the file has not been lost. Anything that is mailed to SSA should be sent "Return Receipt Requested". This way, if there is any question about the receipt of information, the applicant will be able to show the return receipt card, which is proof the information was received and when it was received.

3. My application for Social Security benefits was denied. I meet the Social Security Listing requirements for a person with cystic fibrosis. Why was my application denied?

There are a number of possible reasons for a denial of an application for Social Security benefits. It is important to appeal a denial of benefits, if the applicant meets the SSA medical and non-medical requirements. Sometimes individuals do not appeal a denial of benefits because there is a feeling that if the government has denied benefits the individual must not be eligible for benefits. However, often the denial of benefits is incorrect and after an appeal the individual is able to obtain benefits.

Sometimes Social Security denies an application for benefits because the applicant has disclosed she has a young child. SSA may suspect that an applicant with a young child wants to receive SSA benefits and stay home to care for their children. Being unable to care for a young child, work, and take care of oneself does not make a person eligible for benefits. An applicant must be incapable of full time work due to their own health. The fact that it is difficult to take care of a young child will not make the applicant eligible for benefits.

In addition, some SSA offices are suspect of individuals who stop work and wait a long period of time before filing their application for benefits. Of course, other reasons for a denial of benefits may include the review of a file by someone who does not understand cystic fibrosis and the medical requirements that make a person with CF eligible for benefits.

In addition, certain Social Security offices may not be efficient in processing applications filed at the local office. If an initial application pends for more than five months, an applicant may want to contact their state representative, Congressman or Senator's office to report a long wait for an SSA determination. Sometimes a member of the public official's office will contact SSA and check on the application. However, understand that Social Security offices receive hundreds and thousands of applications for benefits. If the delay is caused only due to a high number of applications filed at a certain office, it will be difficult to have a specific file pulled and a determination made before those applicants that have been waiting for a longer period of time for a decision. ▲

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.

Announcements

VOLUNTEERS NEEDED FOR STUDIES AT NIH

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

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

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

SPIRIT MEDICINE

Let There Be Darkness

By Isabel Stenzel Byrnes

It is winter. The days are shorter and the nights are longer and darker. Winter darkness reminds me of sickness, and therefore, I dread it. But after a recent night hike, I realized that tremendous beauty exists in darkness.

Our culture abounds with metaphors of darkness as negative and light as positive. At best, we depict the goodness of light and badness of dark in our vocabulary; at worst, we apply our cultural preference for light to justify racism. The Bible refers to darkness as sin and the lack of God. In Buddhism, darkness is regarded as ignorance; the inability to see or recognize the truth, particularly, the true nature of one's life. For me, darkness connotes mystery, peace and uncontrollability, but also conjures emotions such as fear and mourning.

"Why do CF patients stay up all night, and sleep all day?" a respiratory therapist asked me once while doing my chest percussion in the hospital. He talked about how many CF patients wanted their first treatments after 10 AM, which the staff thought was way too late. *Probably wired on albuterol,* I thought; but I hypothesized another answer by generalizing my experience. As a child I was afraid of the dark. The darkness meant quiet; quiet meant stillness; stillness meant hearing my wheezing and feeling my shortness of breath and rapid heart rate. Those symptoms would stir up thoughts of impending doom. Better to just stay up.

I was recently reading Sue Monk Kidd's book "When The Heart Waits", where she talks about staying in the dark. Kidd says darkness offers a new way of relating to God. If we wander and encounter darkness, it doesn't mean we are lost. She says God suffers with us and weeps with us through this darkness, and when we recognize this, our darkness becomes a shining thing. There is a holy dark that is part of our journey. Kidd advocates surrendering to that darkness and traveling through to the real light.

Kidd's message reminded me of a job I had while in college. I worked at a day camp that had an overnight. I remember leading young kids on a night hike. We were not allowed to use flashlights, but rather, taught the kids to rely on the rods in our eyes, cells which allow us to see in the dark. Some kids cried about how they were scared and didn't want to walk farther. I held their hands and guided them on their way. I had them describe their fears - mountain lions, snakes, bats - and I explained how unlikely it was that those hazards would be realized during our short hike. As our eyes adjusted we could find our way. If we didn't focus so hard on what was directly in front of us, we could make out shapes of trees, rocks and the path. Sure, we couldn't see color, but we could see almost everything else. By allowing our bodies to adjust, and our minds to relax, we could get along just fine.

Over the years, when I would get anxious at night, I would think of hiking with those kids in the dark. I would relax, not focus on what was scaring me, and just keep moving forward, trusting my vision. Sometimes, however, we enter the darkness and have to sit with it… and be terrified. But usually, something magical happens.

> *"Kidd says darkness offers a new way of relating to God. If we wander and encounter darkness, it doesn't mean we are lost."*

ISA STENZEL BYRNES

I remember my lowest emotional point with CF. I was one month into a hospital stay following a massive lung bleed and short stint on a ventilator. I had had several embolizations. I was on seven liters of oxygen and still streaking blood. I was congested but could not do airway clearance. Then, one night, I woke to gurgling and coughed violently. I turned the light on, and spat into the pink emesis basin I had on my table. Sure enough, it was bright red. I called the nurse. While I waited, I filled the basin up with blood. I couldn't breathe; in between coughs I asked for a mask through the intercom. The nurse arrived with a gauze mask, not realizing that I needed a full oxygen mask; the nasal cannula did not quench my breathlessness. I demanded ice, which she promptly brought me. I held the cold against my chest to constrict the blood vessels. As expected, the bleeding stopped just as quickly as it had started. The nurse left to page the doctor.

As expected following a large bleed, I could feel my rapid pulse through my forehead, as a pounding headache climaxed. I had to turn off the light. I sat upright in bed; too afraid to lie back should the bleeding start again. My head throbbed so badly that I could not move. In the dark, I just sat there. Time passed. Then, the emotional demons started to surface. A wave of hopelessness overcame me and I started to sob. This life seemed pointless. I hated my lungs. I was angry at the stupid nurses and absent doctors. I was terrified of dying alone in the dark. In desperation, I started praying, no - begging - for God to help me. I asked what was he trying to teach me. I wondered if God was listening at all.

Just then, in the darkness, I turned my head slightly to the window. It was late and totally dark outside. As I squinted to ease my headache, I saw a faint speck of light in the distance. The light found me. I couldn't take my eyes off it. I focused on the light and felt a surge of relief from despair. I don't know where the light came from, or what it was, but it filled me with a conviction that things would get better. I thanked God then for that hope.

That is the benefit of darkness. It allows us to start *looking for light*. The light can be outside of the darkness, like the example above. The "light" can be the right medicine, a friend, a discovery or some other gift that comes into our lives. The "light" can also come from within- an emotional revelation, spiritual source of comfort, or an awareness at the perfect moment.

Darkness challenges us to cultivate courage. By first being in total darkness, sitting with it and feeling what darkness has to offer, we then move on to name and describe our fears. We start to pay attention and look around to see what else is out there. We know we have a *choice*. We can stay in the dark or we can start venturing out. Much like the scared children hiking at night, during our metaphorical "walk in the dark", we can examine the path ahead. Even if we can't see the colors, we can make out the shapes. By doing this, we conquer our fears. Richard Wright said, "I would hurl words into this darkness and wait for an echo, and if an echo sounded, no matter how faintly, I would send other words to tell, to march, to fight, to create a sense of hunger for life that gnaws in us all." What a great feeling: to welcome the dark and know we can handle it. For me, my inner warrior shouts out, "Bring it on! Let there be darkness!" because I know I can deal with it. It's not an invitation for darkness, but a confidence that I will survive. Like spring's rebirth after a dark winter, this empowerment of the dark, to me, allows us to truly live in the light.

Another source of inner light is the realization that darkness is a necessary good thing. Our bodies are programmed to *need* darkness to fully rest. I believe that when God said, "Let there be light", that really meant half the world is light and awake, and the other half is in the dark, resting! A lot happens in the dark. Deep beneath the soil, a seed germinates in the dark. Entire animal kingdoms function in total darkness. As a writer, my best ideas come out in the middle of the night. Great spiritual epiphanies happen in darkness. It is believed that Jesus, an instrument of love and hope, was born around the darkest days of winter solstice. Wise Buddhist teachers find great enlightenment when alone in dark caves. And darkness can be beautiful: I certainly prefer darkness in my chest x-ray, because white signifies infection or scarring. We could not appreciate the spectacular fireworks or a shooting star without the backdrop of a black sky.

Today, I experienced the ultimate joy of darkness. I went on a hike with my sister Ana. Ana spent the warm hiking days of summer recovering from her second lung transplant. Her goal was to hike to complete a steep seven-mile loop. We started our hike at 3 PM, in mid-December. With Ana's determined but compromised pace, we reached the summit, the midpoint of the trail, an hour before the sun was to set. Knowing we were up for an adventure, we picked up the pace, but soon we caught the last glimpse of daylight. I had done this before, and my husband chastised me for putting my safety in jeopardy. But I felt confident with Ana and my basset hound guard dog by my side. I wanted to face the darkness with courage, and so did Ana. I reminded myself that there was nothing scary about the dark; it was simply the absence of light.

At dusk, I noticed the silhouettes of the trees and hillsides marking the boundary between sky and land. Everything seemed clearer, refined, precise. As we hauled down the mountain, we entered dense forested areas, just as the first stars shone through the branches. Soon, we were hiking in the

Continued on page 9

WELLNESS

Savoring The Moment

By Julie Desch, MD

I have to confess that I don't often look until the last minute at what the "topic" is for each issue of *CF Roundtable*. Then, at the last minute, I frequently have to wrack my brain to find a way to fuse my *Wellness* focus with the *CF Roundtable* focus. So I just saw that this time, I get to fuse the "power of positive thinking" with using the five senses to improve one's wellness.

This is a bit of a stretch, but here goes. Basically, "positive thinking" is "optimism" or "hope." Optimism and hope are two very significant lines of study in the burgeoning field of "positive psychology." Positive psychology is all the rage. Seriously.

Positive psychology, as described by its strongest proponent, Martin Seligman, focuses on human strength as opposed to weakness, is interested in resilience rather than vulnerability, and is concerned with the cultivation of wellness, not the remediation of pathology.

This is very different from the psychology of old, which was about diagnosing and treating mental pathology. Positive psychology studies what makes successful people tick and how to increase (what Dr. Tal Ben-Shahar calls the "ultimate currency", in his book, "Happier") happiness. Dr. Ben-Shahar teaches the "most popular and life changing course" at Harvard University, a class he describes as "teaching people to be happy."

I'm very into happiness right now. One of my favorite reads of the past month, besides "Happier", is Seligman's book, "Authentic Happiness". It used to be a given that you were born either a "happy" person or not. Happiness was thought to be mostly about temperament, and temperament was thought to be largely genetically determined.

However, Seligman offers a happiness formula, convincingly backed up by research. It is: H = S + C + V, where H is one's enduring level of happiness, S stands for one's set range (sort of like personal characteristics: a fixed level of happiness to which a person returns after good or bad events have passed), C stands for life circumstances, and V stands for factors under one's voluntary control. Essentially, our temperament and circumstances can limit our happiness to a certain extent, but the most exciting discovery is the "V". These are the actions we can take to be happier! And "V" is under our control.

What I am learning is that there are many "habits" to develop that will increase "V". In fact, look for my upcoming book on the topic of increasing "V" when you have a chronic disease (the working title is "Sick and Happy"…publisher yet to be determined). I'm not really joking.

> *"I am talking about paying very close attention to your experience and enjoying fully the pleasant sensations that occur all the time and often escape notice."*

There are proven techniques for improving your happiness about the past (i.e. boosting appreciation and gratitude), the present (i.e. cultivating mindfulness) and the future (i.e. learning optimism and hope).

For today's article, however, I am going to focus on one effective technique involving our senses to increase the "V" in our happiness equation: savoring. Savoring is, obviously, a way to increase our appreciation of the present moment.

To "savor" something is to enjoy it fully, to appreciate it, or relish it. We have five tools (at least) to use along with our mental awareness in doing this. They are sight, touch, smell, taste and sound.

I recently experienced a savoring exercise in a continuing education class I am taking through Stanford University entitled, "Happiness" (I told you I was into happiness.) Everyone in class had a raisin, and we were instructed to eat the raisin as slowly and mindfully as we could, taking note of all the sensations we experienced.

JULIE DESCH, MD

I don't really like raisins, but I did it anyway, and definitely got the point of the exercise. So when I got home, I did the exercise with a glass of Chardonnay. I learned that Chardonnay (at least the one I tasted that night) is SO much better than I thought it was…and I already liked it quite a bit!

Do you ever look back on something you ate, or something you did or saw, and think, "I wish I would have paid closer attention to that, because it was great!"? Maybe you knew a person who is now gone, and you wish you could go back and appreciate more closely how they looked, how important they were to you, how much you loved them.

You can learn how to do this. Actually, you already know how to do this. What you can learn is how to *remember* to do this. It is about two things, slowing down and focusing. With the wine, for example, I often am eating, talking or doing countless other things as I mindlessly sip my glass with dinner. I bring the glass to my lips on autopilot, and often forget to notice the flavor. Then the glass is empty. What a waste!

It's not just with taste that this becomes apparent. Our "assignment" for class that week was to do a daily savoring activity using each of our five senses. For the "hearing" exercise, I decided to take my slightly crippled border collie for a (slow) walk around the block paying very close attention to everything I (he's deaf) heard. Taking Cisco was helpful, because he forced me to go very slowly. I did this in the morning, and then again after dinner. Do you know that I have lived 47 years without realizing that birds don't really sing at night? I pondered that for the rest of the evening.

For me, listening to music also can bring back such vivid memories that I can almost savor a historical event all over again. I listened to James Taylor's newest CD just yesterday, and was literally brought to tears by "You've Got A Friend" as I was transported in time back to a very touching moment I had with my sister, Kathy, when I was about 8 years old. She's been gone now for 24 years, but I got to remember her and how much I felt loved by her, as if I were 8 again.

A sunset would be a perfect thing to savor visually. Or consider the touching example offered by a fellow classmate, who shared with the class how she appreciated for the first time the beauty of her mother's facial wrinkles.

Seligman gives a graphic example of savoring the sensation of touch. Imagine being completely muddy and gross from playing football in the rain…or going on a mountain bike ride in a wet forest, and then getting into a hot shower to wash off the muck. Can you just feel how that would feel? Next time you are mucky, maybe give the mindful shower a try.

Basically, I am talking about paying very close attention to your experience and enjoying fully the pleasant sensations that occur all the time and often escape notice. It's not a difficult exercise at all. You may recall in a previous posting when I rambled on about my hero, Eckhart Tolle, who stresses that, really, all we have is now. The past is a memory and the future is a fantasy. So since all we have is now, it seems that remembering to savor now, and all that now holds, is a good goal to have.

As you experiment with savoring over the next three months, you can look forward with eager anticipation to next issue's Wellness column, where I will wax prolific about Eating, another of the energy inputs in the Energy Management System. ▲

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.

SPIRIT MEDICINE *continued from page 7*

dark. My dog pranced around fearlessly, like a kid in a candy store, with heightened awareness of the smells and sounds of the woods. With my vision dimmed, I, too, could pay attention to my other senses. It had rained heavily the day before, and the earthy air smelled fresh. Mud stuck to my boots as I walked, making squishing sounds. I enjoyed the music of nocturnal insects and birds hidden in the forest.

Occasionally, I was tempted to look up at the sky for guidance. I'd see a flash of brightness from a solitary star or an airplane above. But then, when I looked back at the trail, I could hardly see it. So, looking at the light did not always help to find the way. I kept my eyes on the trail, stepping carefully on the lighter patches of ground, not on the dark patches which were sticks, rocks or loose leaves. We were almost at the end when we got to flat ground. I noticed a lighter area of earth and walked over it. I felt cold on my toes. The lighter ground was a large puddle! I laughed at myself, knowing that lighter ground is not always safer ground.

Writer and psychologist Og Mandino said, *"I will love the light for it shows me the way, yet I will endure the darkness because it shows me the stars."* When we finally reached the parking lot in total darkness, Ana and I stopped at our car and looked up. The dark sky was sparkling with millions of brilliant stars in the winter sky. We gasped at its glorious beauty, since it had been so long since we had observed the stars. This was our reward for our courage. We breathed the cold air deeply and praised God for allowing us to face the darkness together— and then see the light. ▲

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 lives in Redwood City, CA. She invites spiritual writers to share their 'spirit medicine'.

SPEEDING PAST 50...

I'm Positive About Positive Thinking

By Kathy Russell

Wahoo! Another new year! Time sure does fly. 2007 was neither the best nor the worst year ever. It just was. I am not sorry to see it end. I look forward to 2008 with the optimism that has served me well all my life. I am sure that there will be ups and downs, but I am most sure that the year will be what I make of it.

This issue has a Focus topic of "The Power of Positive Thinking." I have heard many discussions of positive thinking. I know there are some people who think we can cure our CF with positive thinking. Now, we all know that is not possible. CF is a genetic disease. No amount of positive thinking can change that. Positive attitude can mitigate it, though.

When we use positive attitudes to deal with our CF, we are able to get the feeling of having some kind of control over CF. (I doubt that we really have any control of CF, but it makes it seem that we have.) At any rate, positive attitudes can make us feel better.

I know that when I am feeling my worst, if I am able to maintain a positive attitude, I do feel less stressed and I seem to get better, faster. Also, having a positive attitude makes life a little easier on those around us. We must remember that our attitudes affect those around us, and we should try to make life a little easier for them, if we can.

I remember times when my physician was very concerned about my state of health. I could sense that concern and felt compelled to let the doc know that I wasn't planning on dying any time soon. By holding a positive attitude about my state of health, I was able to keep from getting into a depressed state and was able to heal more quickly.

Positive thinking may not work well for everyone. It takes a strong mind and will to make it work. Positive thinking can ease the "life burdens" we all face. Just keeping a smile, rather than a frown on one's face, can improve one's sense of well-being. Try it. When you are feeling crummy, try smiling, instead of moping. You may be surprised at how much better you feel. It is really difficult to stay sad or angry, when you are smiling.

I am one of those people who was born "happy". I always have looked at life with a "glass is partially full" attitude. I always have known I was loved, and that has a profound influence on how one perceives life. The sense of "being loved" adds so much warmth and joy to a life. It really helps to make one feel positive.

One pitfall with adopting an attitude of positive thinking is the tendency to blame yourself when you become ill. It is very easy to think that if you only had been more compliant, or only had done more treatments, you might not have gotten sick. While this may be true, chances are that it isn't. We get sick. That is a given. Even if we do everything we are supposed to, and we don't do anything we shouldn't, we still get sick. That is the nature of CF.

KATHY RUSSELL

Positive thinking can't change the nature of CF, it can only assist us in dealing with CF. Even if you have tried it in the past, and it hasn't worked well for you, give it another try. When you wake up, begin your day by thinking "This is a new day and I will make the best of it." Some days, our best may be pretty mediocre. But on other days, our best is pretty darn great. Give it a whirl.

On another note, I just realized that this issue of *CF Roundtable* begins the 18th volume of publishing for USACFA. February 2008 marks 18 years since a few of us began the work needed to form this organization and to begin publishing our own newsletter. We were positive that there would be interest in a newsletter for adults who have CF, and we were correct.

Lisa McDonough had begun the hard task by publishing her newsletter, which was called *Roundtable*. When she no longer could go on, she asked for volunteers to carry on. We would have had a much more difficult job without her great beginning. Those of us who have the four issues she published, treasure them. She did outstanding work. I think she would be pleased to see how the newsletter is progressing.

Over the years, many people have participated in creating *CF Roundtable*. Some have served as Directors and others have written arti-

cles or performed other services for us. Each of these volunteers understood that creating a newsletter is a lot of work but that positive thinking could get things done. I am grateful to be a member of such a loving community.

Although all of the volunteers who have worked on *CF Roundtable* have felt it was worth their efforts, not everyone feels that *CF Roundtable* is a worthy publication. One person asked to be removed from the mailing list, because we printed a story "that featured homosexuality as normal, acceptable behavior." We print stories that feature all sorts of things that one person, or another, may find to be outside of their particular comfort level. We don't make value judgments on what people write. As long as their writing isn't blatantly crude or obscene, and their topic is relating to CF, we let it go.

Another person wrote to chastise us for printing photos that showed people with CF standing side-by-side. She pointed out that the article on page 1 of the Autumn 2007 issue said, "The three foot rule means that no one with CF may be seated directly beside another; also there is no common handling of dishes or pens." She asked, "So it is not O.K. to sit down for dinner near another cystic, but it is O.K to stand next to them??" She continued, "This type of hypocritical mission is the cause of other cystics not trusting organizations like yours, you say one thing and do the opposite (thinking you're not being watched.) … This is why I don't want my children to read your newsletter as they pick up on these things and when I tell them they cannot be around others with CF, they claim that it is OK because they see others do it."

We responded by saying, "Thank you for your e-mail regarding observation of the 'three-foot-rule'. We appreciate your comments.

"You have every right to keep *CF Roundtable* from your children. As a matter of fact, *CF Roundtable* is not intended for children. If you will notice on the front page of each issue, it is clearly stated that this is "A newsletter for adults who have cystic fibrosis." We never intended this newsletter to be read by children. Their needs and problems are different from ours. Parents of children who have CF may find useful information in the newsletter, however, and we encourage them to read it

"As to photos that show us standing near each other, we are adults and we can make informed decisions for ourselves. We choose to stand near each other for the duration of a photo. At all other times, we do not stand or sit next to each other. Even in our support groups, we leave the space of a chair between us and we do not sit directly opposite each other, while we are at a table, even in a restaurant.

"It is my hope that with research and better treatments for CF, your children may live long enough to not have to worry about cross-infection issues. Until then, you must do what is, in your opinion, the best for your children.

"Thank you for writing,"

So we go on. We can not meet all the needs of every reader. We would be foolish to try. We can try to do the best we can at presenting varied ideas and viewpoints from many different people. Our readers are our writers and they make the newsletter what it is.

So, you may be asking what all this has to do with a positive attitude. I can understand your confusion. On the one hand, I am talking about positive attitudes, while on another I am talking of people who are unhappy with what we are doing. They really do go together. I am positive that a newsletter for adults who have CF is a wanted and needed thing. Also, I am positive that no matter how hard we work, there still will be some people who are unhappy with us. We can't let that stop what we do, but we can learn from it and try to do better.

After 18 years of volunteering on USACFA, I still feel that my time is well-spent. I have met so many wonderful people: by phone, e-mail, letters, and in person. My life would be poorer without those people.

This is my last year as Treasurer and as I withdraw from an active role in USACFA, I promise that I will continue to stay in contact with my friends. I will have more time to spend with my wonderful husband and I am positive that this will prove to be very valuable to me. I will have more time to make jewelry and Raggedy Ann and Andy dolls. It is quite a while since I have had time for that. I will enjoy my leisure time.

Having a positive attitude about life has enabled me to accomplish many things. I am positive that it will continue to serve me well, as I age. I figure that any day that I wake up is a good day. No matter what is going on, if I stay positive, I can get through it. So far, that always has been true. I hope it will continue to be.

This is the time for you to step up and get involved with USACFA. Write an article or volunteer to help in some other way. Make a monetary contribution, if you can afford it. Encourage someone else to write, or volunteer, or donate. We always can use the help. This newsletter is yours. It can not continue without your participation. I am positive that each of you can (and will) help to keep *CF Roundtable* going strong.

Have a healthy, happy 2008 that is full of good health, love, laughter and peace. ▲

Kathy, 63, has CF. She is a Director of USACFA and is the Treasurer. Her contact information is on page 2.

FOCUS TOPIC

THE POWER OF POSITIVE THINKING

Awakening

By Dave Davison

DAVE DAVISON

Last Thursday I returned home from the hospital. I negotiated my way down to only nine days instead of the planned 14. Had it not been for my wife promising the doctors she would make sure I did all my treatments, I'd still be there. Thank you dear!

When I entered the hospital this time, it had been after a several-week struggle of a tight chest, shortness of breath and an extreme lack of energy. This was only the second hospital stay I've had due to cystic fibrosis (CF). I had contracted methicillin resistant staphylococcus aureus (MRSA) during the first sinus surgery I had last year and it was beginning to get the best of me. I didn't like the idea of having to go in, but I was tired of being so tired and I knew it would help.

My sixth day there, they put a young lady in the room next to me. I knew she had CF even though they hadn't posted a sign outside her door. It's not hard to spot all the other rooms that have CF patients in them. There is the sound of a percussor coming from behind a closed door, a calorie intake sheet taped along side the red 'STOP' sign (indicating that gown and gloves must be worn when entering,) and, finally, the yellow cart marked 'ISOLATION' parked in front of the room containing said gowns, gloves and masks. To me it was obvious she had CF, but those were not the reasons. It wasn't her appearance either, because I saw only a glimpse of her. It was the horrible constant cough. It almost didn't sound human to me and her voice was a shallow, raspy whisper. It scared me. The consequences of CF seemed to hit me for the first time.

> "My goal then was to be just like all the other kids. I ran, jumped and played just as hard as all my friends no matter how hard I had to fight and struggle to do so."

My overall health has been fairly good and though my grind with CF began many years ago, I just didn't know it. I was diagnosed at the age of 34. I am now 46. I have always felt blessed that I was diagnosed so late. Not knowing what was wrong with me, I thought all I had to do is fight through the current problem I was having and then I'd be fine.

When I was a child and young adult, those problems with CF came in the form of a constant stream of sinus polyps and subsequent surgeries. Yes, there were breathing problems too, but at my young age I thought it was because of my sinuses.

My goal then was to be just like all the other kids. I ran, jumped and played just as hard as all my friends no matter how hard I had to fight and struggle to do so. I would not allow myself to stand out as "sick", or "slower", or "not as good as" everyone else. I believe it was my attitude *then*, that helped me physically as time has continued. It kept me active and it kept

me ignorant of what I was up against.

So, now that you know how I got here, let's talk about today. I am grateful for today and looking forward to all my tomorrows. It was looking at the tomorrows and hearing that young lady in the hospital room next to me that made me so scared. For the first time, I saw what tomorrow could bring and it's forced me to do some hard thinking.

Over the past 12 years, since my diagnosis, I've been living with the knowledge of CF but not the reality of it. I've been looking at it from the outside like I was alone and unique in my situation. Many things about this trip to the hospital have brought CF front and center. One of those was being introduced to the *CF Roundtable* newsletter. I was handed a binder full of issues and as I began to read I realized I wasn't alone and CF is a real part of my life. (Something my doctor had been telling me for years.)

I started taking inventory of the last few years and found that I had better sit up and start paying attention. Three years ago was my first hospitalization. Two years ago I had ABPA (allergic bronchopulmonary aspergillosis) which had me down and out from September until April. (Hated the steroids.) Every fall, it seems easier for me to start having problems and my PFTs proved it. Instead of having "MILD CF", all my records now indicate "MODERATE CF". Yes, for the first time, I have realized I have a membership card to the CF club. It doesn't matter that I didn't send in an application, or that I don't want it. I can't refuse membership.

I also realized I was still that same little boy who fought so hard to be just like everyone else. I'd been trying to live my life as if there was nothing wrong so no one would look at me like it was. All those years of convincing myself I was okay and not letting anyone see any weakness was still forming my actions; this time to my detriment.

Yes, I've learned a lot about myself these past few days and I've learned all of you are right there with me. I think the best thing to keep in mind, as we live our lives with this disease, is that we are not alone. We can learn from one another and hold each other up through our experiences and our knowledge.

> "We can learn from one another and hold each other up through our experiences and our knowledge."

Here is what I determined. It may sound simplistic, but if you have to break it down to the basics then that is exactly what you must do.

- CF, as with any task we undertake, must be done with a plan and a goal in mind.
- It is not easy to comply with treatments. For me it was hard even when I tried half-heartedly. So it won't be any easier doing it as I'm supposed to. Let's face it, daily time with nebulizers, vests, sinus irrigations and pill after pill is a pain. How do you fit all of it into a normal day?
- Becoming disciplined in your approach is key. Schedule your daily treatments and be determined to follow through. If something keeps you from your schedule, be persistent in completing your treatment at the soonest available time.
- Figure out where your stumbling blocks are and find solutions to overcome them. Write it out. Sometimes I find it easier when I have it in black and white. I can go back and look at it when I need to.
- Keeping a positive attitude is essential. Make things fun and look for the "funny" in all situations. I made it my goal to make every hospital staff member I dealt with either laugh out loud or at least smile. I wanted them to feel good when they left my room. And that made me feel good!
- Life always throws curve balls. At least with CF we know what the next pitch is. Use that knowledge to your advantage. Take your best swing!
- Remember...we cannot depend on others to make us do our treatments. Even though our families love us and want to help, we can burn them out with a continued lack of trying and a poor attitude. In the end it is up to you, no one else.
- Most everyone has a sense of "spirituality". Mine is a faith, trust and relationship with my Savior. Use your faith. Know what it is you believe in and why.

So this is my plan. I hope that I have joined many of you in similar commitments to the way you live with CF. I also hope that others will join by implementing these plans and even expand upon them. In each of us there is unique knowledge and lessons learned. Let's turn to one another and build our strengths through sharing our hopes, experiences, laughter and yes, even our pain. ▲

Dave and his wife, Julie, live in Council Bluffs, IA. Dave works for a printing company in Omaha, NE.

The Power of Positive Thinking

By Heather Summerhayes Cariou

I was six years old and my sister, Pam, was four, when my mother came into our bedroom, gathered us up onto our pink chenille bedspreads, and told us that Pam had something called cystic fibrosis (CF). It was 1958, and very little was known about CF.

"Some children die of this disease," my mother told us, her throat splotchy and her face red from holding back her tears. She explained that dying meant leaving our home on earth and going to a new home with God. "Everybody has to die, even Mommy and Daddy will die someday. But that time is a long way off, I'm sure, and in the meantime, we will do everything we can to make Pammy well. We will never stop fighting. We will never give up."

With the advent of my sister's diagnosis, it was as if my family had crossed the waters to a foreign land. Essentially, we became immigrants in our own lives, leaving behind our identities and relationships as we had known them, losing the future we might otherwise have imagined for ourselves. Even at my young age I had the sense that life would never open up before me, for it had instead opened up beneath me, and I felt I was falling.

I promised Pam I would die with her. Little did I know that we were only at the beginning of a long journey together, and that we would in fact teach each other how to live. We learned from one another how to find joy and meaning in a world full of pain and uncertainty. We helped each other restore our faith in life when all seemed lost. We laughed together as we never laughed with anyone else, at moments and for reasons that were inexplicable to others, but made total, silly sense to us.

HEATHER SUMMERHAYES CARIOU

> "Pam also taught me that you can't control life by being afraid of it."

When Pam was ten, she encountered the first of several life and death battles with her disease. She won, but not before locking herself in a hospital bathroom and going through the kind of deep-soul searching a child should never have to face.

"What I finally realized," she told me later, "was that God gave me a life, and it's up to me to live it the best I can, for as long as I can." "Don't worry," she promised, "I'm not giving up."

And she never did. At the moment she died, at the age of 26, those were the last words she uttered; "I'm not giving up."

In that, Pam has left a legacy for me and for anyone whose life is touched by illness, loss, or anything that presents itself as an obstacle. Never give up.

There were many times Pam had to surrender – her physical abilities, her goals and dreams – but never without a fight, and never without understanding the difference between giving up and surrender. Giving up implies there's still some fight left, some unfinished business or unrealized potential that's being tossed aside. It's an act of anger or despair. Surrender means we know we have given all we can to something or someone, and accepted all there is to be received. There is compassion in surrender, both for ourselves, and for the thing we leave behind. It is an offering, a gift.

Pam also taught me that you can't control life by being afraid of it. Like Helen Keller, Pam believed that security was a superstition, and that life was either a daring adventure or noth-

ing. She overcame her fears by focusing on joy; by creating it for herself and for others, whenever possible.

She knew she was dying when she wrote, "I enjoyed most every moment of my life, whether it was up or down...there was always something to learn from, and there was always something in the world that was beautiful that you could take from, and every experience could mean something if you looked at it that way. If we take the chance and opportunity of seeking out beauty in the world about us, every moment of every day can be treasured."

Pam had studied the work of Holocaust survivor Viktor Frankel. "We may not be able to choose our circumstances," she quoted to me, "but we can choose our attitude toward them. Everything can be taken from you, but you still have a choice how to respond."

Frankel reinforced Pam's own thinking that the sort of person she became had more to do with her inner decisions than the circumstances in which she found herself. She realized that the way she bore her suffering could be a genuine internal achievement. Again she quoted to me, "It is this spiritual freedom – which cannot be taken away – that makes life meaningful and purposeful."

Pam endeavored to change her personal tragedies into triumphs, making her life a work of art in and of itself, as one might take bits of broken colored glass and create a beautiful mosaic.

My sister's choice to remain positive and her refusal to be defined by her disease led her on a journey whereby she outlived her initial prognosis by twenty years, finished high school, made the Dean's honor list at college, and ran her own daycare as an Early Childhood Education teacher.

I am continually inspired by her legacy as I live my own life, and equally inspired by witnessing the power of the positive in my youngest brother, Jeff, who also has CF. He just turned 46. He's been a blacksmith, a horseback rider and trainer of show jumpers, worked on the line at Ford, and in his latest incarnation, he's worked as a white-water rafting guide and rescue expert. A recent lung infection is slowing him down only a little – he makes the effort to bicycle several mornings a week from his home to a favorite breakfast spot a couple of miles away.

> "'If we take the chance and opportunity of seeking out beauty in the world about us, every moment of every day can be treasured.'"

Seeing what my sister and brother have made possible for themselves, against the greatest of odds, has taught me to look at my own life as an adventure. Both Pam and Jeff have taught me to use my strengths in service of my life, and not dwell harshly on my limitations. I've learned from them to think of what I can do with what I've been given; and if in trying I find it's not within my reach, I know not to waste time or energy bothered by what I can't accomplish. (I never use the word failure.)

When my brother is out on the river, plying the rapids, he must be aware of the obstacles, the rocks and whirlpools, but his focus is always on finding the way through. And though the ride is sometimes scary, and takes a lot of effort, there's always a whoop of joy and laughter in there somewhere. That stands as a powerful metaphor for him when he's back on land, on the days when he's struggling just to breathe. It stands as an equally powerful metaphor for me.

Positive thinking does not mean wearing rose colored glasses or living in denial. It doesn't mean that you don't experience dark days and long nights. It means gaining strength, courage and confidence every time you stop to look fear in the face, and building on that to tackle the next challenge. It means understanding that we are our choices, not our circumstances. It means choosing life, even in the midst of death.

Life has taught me that there is no happy ending. But there is the day. The sun, the rain. The chance to say I love you. The willingness to forgive. The courage to remember. The opportunity to be kind. The ability to laugh and to be generous. The fact that we can choose our joy in each moment, no matter what.

Knowing that choice is ours helps Jeff and me survive, and lets Pam survive in us.

With faith and joy... ▲

Heather Summerhayes Cariou, 55, does not have CF. She is the daughter of the founders of the Canadian Cystic Fibrosis Foundation, and author of the newly released "Sixtyfive Roses: A Sister's Memoir". She and her husband, actor Len Cariou, live in West New York, NJ. She's been a resident American for 24 years. For a number of years, Heather served on the Board of the New York chapter of the CFF. During that period of time she helped organize two tri-state conferences on CF, and her husband sponsored several Len Cariou Entreprolebrity Golf Tournaments for CF.

How I Stay Positive With CF

By Meranda Honaker

I believe positive thinking is a *must* when dealing with cystic fibrosis or any other illness. As I will show through using examples of my own life experiences, staying positive can help CFers through some difficult times. However, staying positive is not always easy, which is why I will pass along the things that help me remain positive and upbeat. It's easy to give in to difficult times and not every day is a good day. Sometimes we get good news from the doctors and sometimes we get bad news, but how we react to this news is usually indicative of how we will cope with the underlying issues. Finally, the people you surround yourself with can have an enormous impact on your ability to remain optimistic and positive.

I've had many tough spots in dealing with CF over my lifetime. I don't know a single CF person who hasn't gone through difficulties. One of the hardest times for me was when I began experiencing symptoms of gastroparesis - a condition where the motility (speed) of the stomach becomes slow or paralyzed. The symptoms are severe with nausea, vomiting undigested food, bloating, reflux, heartburn, appetite loss and weight loss. I suffered for three years with the mentioned symptoms and after seeing three Gastro doctors I often became very discouraged. I felt like a shadow of my former self, due to the weight loss and nausea. To top it all off, I could not find a doctor who would take my symptoms seriously. It was very disheartening to say the least.

I began to lose hope, not only about feeling better, but I lost faith in the medical community as well. However, the love of my life (Michael), my parents, Pastor, and church family continued to show me endless support and encouragement. It was because of their love, encouragement, and endless prayers I continued to fight and remained hopeful that someday I would be able to eat a meal again without getting sick. It's now four years after I first began experiencing symptoms of gastroparesis and for the last year I have been eating normally, as long as I take my promotility meds. This has resulted in me regaining over thirty pounds, most of it from Mexican food and good ole' home cooking!

> "The people you surround yourself with can have an enormous impact on your ability to remain optimistic and positive."

Yet another example of the benefits of staying positive was my recovery from my last sinus surgery in September 2007. The first week afterwards was very difficult. I became frustrated and wondered if I would live with chronic sinus infections for the rest of my life. The pain after this surgery seemed far worse than what I remembered from my first sinus surgery, and my recovery was taking longer than what was expected. It turned out I had an oral thrush infection which was causing the pain in my mouth, but it was nonetheless painful. However, I remained positive that I would feel better and it was just a matter of time.

When I was feeling bad physically I would sit in my recliner, get my notebook, and write my feelings down in my journal. I often have to be reminded to be patient because getting better takes time. If I didn't have my loving and positive support system to remind me of this simple fact every day, I would have allowed my emotions to completely match how I was feeling: bad. My family said every day that "you will get better, just be patient and don't let this get you down". Obviously, I did get better and remaining positive made it less stressful. I will also add that my ENT (Dr. Brent Senior) is wonderful, and he always remains optimistic when treating my sinuses, which helps me remain positive.

Now I would like to share with readers how I remain optimistic despite CF. I try not to pay attention to the life expectancy statistics of people with CF. Average life expectancy statistics can be very discouraging to dwell on. Instead, I like to think about the many people with CF who are living into their 50s, 60s and even 70s. I also like to read about the many medications that are being studied to manage CF. This gives me hope that we will have more options to treat CF in the future.

One of the main things that helps keep me positive is hope. Hope for better treatments, hope for improved quality of life, and hope for a cure. I believe that without hope we have nothing. Also, When I see my lung function has declined I begin asking

myself "what else can I do to improve my lung function" and I never give up hope that I *can* improve my lung function. I've known some CF patients who don't believe they can improve their lung function. But, that's looking at it negatively and it's simply not true. A CF person's lung function often can be improved. There have been times when I, too, felt pessimistic about having CF and about my future. But, because I remain hopeful, I am able to stay positive.

Additionally, one of the many things that help me stay me positive is having an excellent support system. I have realized that when I surround myself with caring and positive people, their attitudes rub off on me. But, the opposite can happen as well. I have realized it's best to distance myself from negative people because misery enjoys company. God, my Pastor, church and family are a big part of my life. I know I would not be the person I am today without them. My Pastor (Tommy) helps me remain positive by always offering me an encouraging word. My adopted grandparents, Carrie and Eddie, have also been a blessing in my life. I know that I can always pick up the phone and call them and immediately my spirits are lifted. I don't think words could ever express the gratitude and appreciation I have for my Pastor and church family. It's easier for me to stay positive, despite any negative circumstance, because of their love and encouragement.

It's normal for us all to feel frustrated in dealing with CF. But, we must not remain frustrated. I find it easy to get things off my mind by writing, reading, praying, or listening to uplifting music. It's best to get all the negative feelings out so that we can make room for the positive feelings. When you think positively, you will find that you deal with stress much better than you would if you were pessimistic. I also have learned that if I wake up each day and begin thinking about all the good things in my life, and thanking God for them, I tend to not dwell on the negative things. It's much easier to think positively when you are focusing on the good things in life, rather than the bad.

A few years ago I was thinking about my life. I realized that without hope, I have nothing. I believe that when we are hopeful we are thinking positively. Sometimes we hope for things that never come true, but if we don't hope for things in life, such as a cure for CF, it becomes very easy to become pessimistic and depressed. I have also found that exercise helps keep me positive because it's a great stress reliever, and it shows me that I am capable of reaching workout goals just like any non-CF person. I also enjoy talking to others with CF and sharing personal stories of living with CF. It really helps to know that you're not alone in this fight with CF, there are others out there fighting CF, too.

> "It's much easier to think positively when you are focusing on the good things in life, rather than the bad."

One of the big life lessons I have learned along the way is to stop caring what anyone says or thinks about me, because you can not stay positive if you do. The best example of this was when I began dating my soul mate, Michael. His sibling thought it was selfish of me to date him. His reasoning was that I would put Michael through too much stress, because of my health problems and by the potential of dying young.

When you go into a relationship with someone you don't expect to be viewed as unworthy just because you have an illness, but it happened to me. This made me feel terrible about myself and caused me to have low self-esteem for quite some time. I also began to feel guilty for being in the relationship, as if I weren't good enough to be loved. These were all negative thoughts and it caused me plenty of emotional stress.

Thankfully, Michael didn't care what anyone had to say about me or my CF because he accepted me, CF and all. I eventually stopped caring what anyone thought about my CF. His sibling changed his tune after getting to know me and apologized for his attitude towards our relationship. Although this was not a pleasant experience, I choose to focus on the good that came from it.

I no longer see CF as a "secret" I have to keep from others for fear of being judged. I never again will be ashamed of having CF. This all goes back to my advice to surround yourself with positive people. If someone has a problem with you having CF, then it's best to distance yourself from them. When we surround ourselves with positive people our whole outlook on life can change, and the same goes for negative people.

Finally, I have also come to the conclusion that I deserve the very best life has to offer, just like anyone else. I'm not less worthy of good things because I have CF. In fact; I feel I am more entitled to the good things in life because I do go through difficulties with CF on a daily basis. I know having a positive attitude about CF, as well as a wonderful support system, has helped me get through the difficult times in life. ▲

Meranda Honaker, 24, lives in Fayetteville, NC. You may reach her at: Meranda22@aim.com.

Positive Thinking: A Cautionary Tale

By Tiffany Christensen

> "There is great value in positive thinking—it has been an important tool to help me get through dark times."

"If you believe you are healthy, you will be." These words echoed through my ears, repeating themselves in my head like a song stuck in my neural network. I had been living in California for over a year and had worked hard to embrace these new ideas I was being taught. I was going to change my destiny with the power of positive thinking.

At 24 I had been told by my doctors that it was time for me to get a lung transplant. I was put on the list for new organs and decided to spend my time waiting in San Francisco, far away from my East Coast home. Once I arrived I began pursuing my desire to deepen my spirituality and explore the possibility of healing through prayer and powerful thought. My ultimate goal was to avoid transplant altogether.

My teacher, an impressive woman I shall call "Tisha," had an approach to life very similar to the ideas expressed in many of the new healing philosophies emerging today—they were along the same lines as the popular book "The Secret." She convinced me that illness was a choice and, by that logic, I could just as easily choose to be healthy. I prayed for health. I used visualizations and affirmations to see my body transforming into health. I cleared my internal thoughts of the belief that I was a sick person. I was inspired by the stories of the people who had used these same techniques and experienced relief from cancer or AIDS. I believed that through the power of positive thinking I could heal myself of cystic fibrosis.

Over time, I did begin to see changes. I discovered the impact prayer had on the course of my life. I felt connected to The Divine in a way I had never felt before. Transformation was happening—that is, in every area but my health.

TIFFANY CHRISTENSEN

Despite my diligence, I still was spending countless days in the hospital and on IV medications. All of my positive thinking seemed to have little effect on my lung infections—they kept on coming with no sign they were responding to my new belief system.

After a year, I began to feel like a failure. When I asked Tisha why I had not seen the changes she told me were possible, she responded by saying "You can be healthy if you want to be; you must not want to be." I thought I wanted to be. I had done everything she had told me to do. There was nothing I wanted more than to be rid of this disease.

Believing it was my fault that I had not overcome cystic fibrosis, I fell into depression. I blamed myself and thought that I must not have prayed hard enough or been strong enough. Perhaps if I had been a better person or loved God more I would have been able to succeed in healing my disease. I wondered if, perhaps, deep down I really did not want to be well.

I lived in California for nearly three years, all the while desperately trying to find the solution to my illness and a way to avoid transplant. Eventually, I had to give in. My health had gotten so poor that I could not live so far from my family any more. I had to admit I couldn't keep living the way I was. It was time to move back to the East Coast and have a transplant.

In April of 2000 I had my first lung transplant. In 2004, due to chronic rejection, I was blessed to have a second transplant. In that time frame, I have lived a life filled with joy and deep breaths. I often think back to the time when I so desperately tried to heal my genetics with positive thinking. It makes me sad to think of that girl who blamed herself so harshly for something outside of her control.

I am a strong believer in looking on the bright side and working for the best possible outcome. There is great value in positive thinking—it has been an important tool to help me get through dark times. Having said that, there is a balance that must be struck when using this type of philosophy in response to an illness like cystic fibrosis.

I do not doubt that there are people who have experienced miraculous healing but those are the few, not the many. Often people like Tisha will cite those one or two examples as a way to "prove" their point. I suppose it proves a possibility but it also presents the opportunity for someone like me to feel like a failure. The truth is, there are many more people who *do not* experience a miracle than there are those who do. We can not judge ourselves using their stories as the ultimate goal. If we do, we set ourselves up for great disappointment.

> "I may not be able to change my cystic fibrosis gene but I can change the way I feel about it."

In my life, I have come to discover there is another kind of miracle besides unexplained healing. There is the miracle of loving life despite having an illness. As an earth-bound creature, I must live by the laws of this earth. One of those laws is my genetic make-up. I may not be able to change my cystic fibrosis gene but I can change the way I feel about it.

For me, cystic fibrosis has been an extraordinary teacher. It has provided me with a greater capacity for compassion and joy; it has led me to take risks and follow my dreams; it has made me a resilient person and someone who appreciates her time here on earth. In a way, the lessons I have learned from this disease are a miracle in themselves. I would not change a thing.

When the illness road gets scary and uncertain, it is easy to turn to people like Tisha, who seem to have all the answers. We all must find our own way to our own kind of healing, so I don't discourage anyone from looking for answers like I did when I was 24. What I do want is for people to understand the pain that can come from embracing positive thinking as a cure, should the efforts result in "failure." If you decide to embrace this philosophy, it is important that you understand its power and its limitations. When used wisely, it can have wonderful healing results which have nothing to do with your body. ▲

Tiffany Christensen, 34, is a resident of Chapel Hill, NC. She gives talks/workshops on Patient Advocacy as well as speaks to health care professionals about the Patient Perspective. In October of 2007, her first book "Sick Girl Speaks!" was published. E-mail inquiries to: tiffany@sickgirlspeaks.com. Also, be sure to check out the website at: www.sickgirlspeaks.com

Mailbox

The enclosed contribution is to honor Pammie Post on receiving the 2007 Jacoby Angel Award. We are proud to call her a good friend to our daughter, Ilana, who died nine years ago. Congratulations, Pammie, on a well deserved honor.

Sandy and Sid Rabinowitz
Burke, VA

CF Roundtable is well written and covers so many features of interest to those with CF as well as those not afflicted by this disease.

Sincerely,
Jay M. Wright
Enfield, CT

The consistent top quality of *CF Roundtable* sets a high bar, and is a wonderful model for how to do this kind of thing well. I always recommend your newsletter and participation in USACFA to adults with CF and to parents of "almost adults". Thank you so very much for the coverage of the CFRI Conference.

Warmly,
Carroll Jenkins
Executive Director, CFRI

I just received my first issue of *CF Roundtable*. Wow, it's great! I'm only sorry I didn't subscribe sooner! I'll fill out the form and send a donation.

Thanks,
Jeff Grosse
Lansdale, PA

Keep up the great work on *CF Roundtable*. Thanks!

Kelli McElhone
Lubbock, TX

Your articles are inspirational. As parents of two boys with CF, we await the time our boys will be ready to read *CF Roundtable!*

Name withheld
at writer's request.
Brooklyn, NY

The Power of Positive Thinking Brought Me Down

By Janice Tate

Any guilt I already felt for becoming sick was multiplied greatly after being exposed to the Positive Thinking Camp. Already when I would get sick, my mother (and I) would ask, "What did you do wrong? Did you stay up too late or skip a treatment?" Now I had the added burden of, "I wasn't positive enough."

After all, people had been encouraging me to "Stay positive!" "If you think you are well, you will be well." So it seemed all I needed to do was believe that I would not get sick and then I would remain well.

But of course that didn't happen.

One day I was at a meeting with lots of people who were into the Power of Positive Thinking. The people I sat with won a contest and said, "We knew we'd win. We remained positive." Earnestly I asked them, "How were you so sure you would win, when someone else out there was also thinking positive that they would win?" They told me because they were motivated with the thought that they would win, they took the action necessary to get lots of entries into the contest.

Finally a little light of truth was shone. I began to realize it was not just the thought/thinking that can cause something good to happen. The positive thinking helps fuel the action needed. Not that I had stopped doing my required treatments before. But maybe with that new understanding it was easier to accept the need to do treatments.

Still, if I got sick, there was the question, "What did I do wrong?" Finally I learned that some things really are beyond our control. No matter how well I take care of myself, or how positive my approach is, there are things, like germs, that can stir up trouble.

Learning that I did not have control over everything was actually very freeing. It was a relief to know I wasn't fully responsible for life's outcomes. Perhaps the lack of control could have caused me to say, "Why bother?"

But the fear and depression that could have come from feeling out of control have been replaced with hope and joy. The stronger my faith has become, the less fearful I am. Sure, I am not in control; but our God, who really is in control, is a loving God. It is my faith that gives me a positive attitude. Relying on my own positive thinking caused me to neglect the real source of power. I have found that prayer to God Almighty is the "positive thinking" that releases a very real, loving power. ▲

Janice, 43, has CF. She and her husband, Robert, who also is 43and also has CF, live in Streamwood, IL.

Start The New Year By Meeting Other CF Roundtable Readers In MySpace!

USACFA has created a new online forum for our readers. We invite you to discuss any articles and/or topics we publish in our quarterly newsletter. Have you read a book we've recently reviewed? Did one of our stories/photos/poems inspire you? Do you know more information about an issue/science article we've noted? Would you like to know how other readers responded to a particular article? Be thoughtful, be creative, but most of all, be vocal!

You'll need a MySpace account (at www.myspace.com), which is free. If you need any assistance with this, contact USACFA Directors Kurt at krobinson@usacfa.org or Cynthia at cdunafon@usacfa.org. Then, visit us at http://groups.myspace.com/cfroundtable. (Note: go directly to the address given above, rather than using the group search function.) Once you're there, you can read any of the previous posts, but you'll need to join the group in order to post your own responses. Since we're moderating initial requests to join the group, so as to screen out spammers, it may take a day or two before you'll be able to post your first message. After that, however, you're free to respond and post anytime you wish. We want to hear from you…early and often!

See you in MySpace!

Surf and Air

Photo by David Myers

Feeling Life
God, Life and the pursuit of waves!
How does one delineate a feeling that words only consume?
Water rushing upward between my fingers
Watching Mother nature perform an act with grace
Anticipating a phenomena day after day that was created before man.
Predicting what will happen with the accuracy of a negative number.
One moment calm and serene,
The next you're praying to God for strength!

Fun no matter what the size.
Warm to the touch.
Cool, sometimes, so cold it hurts!
Surfboard, wet suit, shorts optional and a bar of wax.
All you really need is your birthday suit!

God is the only thing more beautiful.

Water flows towards the golden sand.
Forces come together from above and below my vantage point.
Few in the world have enjoyed this,
And some would love to experience this freedom!
Yet
Others would rather cut off a leg than be there!
I would give my right eye to continue riding the waves!

I keep going, day after day.
My pursuit of life becomes harder each moment I exist.
Man has extended my life.
At what cost?
Man's devices are my weights of life.
Yet
I enjoy them.
For they have been tools given by God.
Whether it be knowledge or hardware
I exist another day.
I rejoice.
May the water flow between my fingers
One more time,
Before I say Good-bye.

Smile
You take your memories with you.
I wonder if surfboards count?
Frustration
Happiness
Anger
Fear
Freedom
Is this the place so many search for?
Is this what I am searching for?
It is called so many different words.
I call it the Green Room.
This is where I am closest to Mother Nature and the Holy One!

– Phillip Howell

FROM OUR FAMILY PHOTO ALBUM...

ANDREA EISENMAN AND ERNIE BIRNBAUM, HER BOSTON TERRIER.

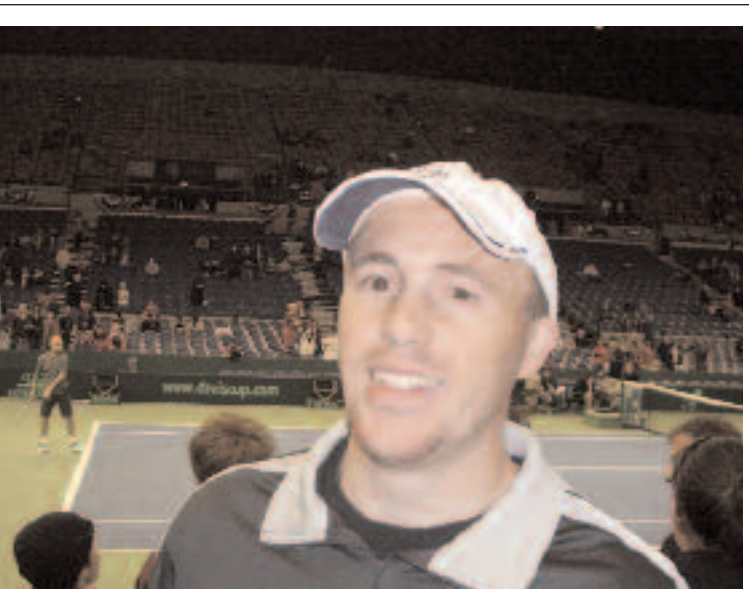
DAVE DAVISON

ISA STENZEL BYRNES HIKING IN THE SIERRA NEVADA MOUNTAINS.

NAHARA MAU, ANA STENZEL AND ISA STENZEL-BYRNES CELEBRATING NAHARA'S 7TH TRANSPLANT ANNIVERSARY AND THE "POWER OF TWO" BOOK.

Photo by Janette McVey

DAVID LEE



KURT ROBINSON AT THE DAVIS CUP TENNIS FINALS.

MERANDA HONAKER, EMERALD ISLE, NORTH CAROLINA IN JULY 2007.

BOOK REVIEW

The Power of Two: A Twin Triumph Over Cystic Fibrosis

By Isabel Stenzel Byrnes and Anabel Stenzel
University of Missouri Press, Columbia, MO 65201
Copyright © 2007

Reviewed by Katrina Bischoff-Howell

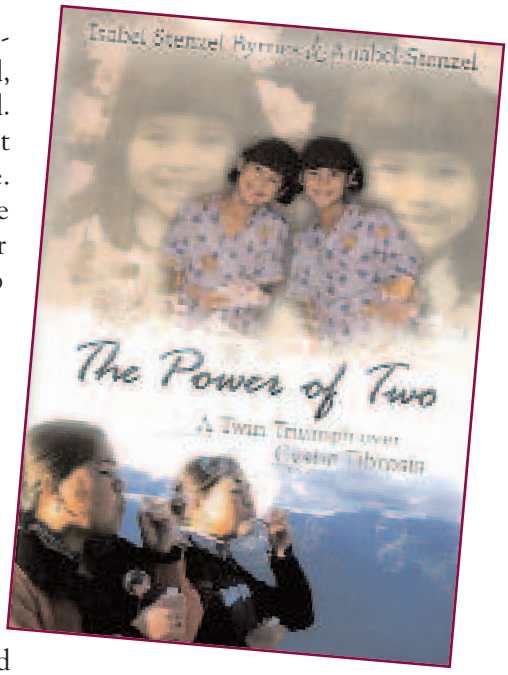
As the title suggests, "The Power of Two: A Twin Triumph Over Cystic Fibrosis" is a fascinating memoir written by twin sisters who have cystic fibrosis: Isabel Stenzel Byrnes and Anabel Stenzel. Both women were diagnosed with cystic fibrosis as infants and received life saving bilateral lung transplants as young adults; Ana at twenty-eight years of age and Isa at thirty-two years of age. Isabel and Anabel openly share their steadfast family support, along with the stress that occurs in a family affected by CF. They candidly discuss their uniqueness of being half Japanese and half German and being diagnosed with CF; and the nuances of growing up first generation American. "At the time, the data showed that only one in 90,000 Asians carried the CF gene (p. 9). And one in 25 persons of Northern European ancestry are carriers. " (p. 9)

This is their life story about how they achieved their goals and ambitions, master's degrees and employment in the health related fields, despite the tedious and often exhausting medical regimens and CF-related exacerbations that many of us are familiar with. It is interesting to read an autobiography written by two individuals, rather than a single author. I especially enjoy how Isabel and Anabel alternate writing chapters in their book. The reader is able to see how they viewed the same situation through different lenses.

This is seen when Isa begins getting more serious with her boyfriend, Andrew, who is now her husband. Ana remarks on her feelings about Andrew entering her sister's life. "Now that the two lovebirds were finally together, their affections for each other made up for their two years apart. I saw an Andrew who was new to me, different from the harmless undergraduate who had dated my sister." (p. 197) "Andrew's presence now drove a wedge into the relationship that had sustained us for so long." (p.199)

People with CF may find similarities in their own lives when Isabel and Anabel describe how their own medical care changed throughout the past thirty years. People currently listed for transplant, or others who already have received 'the gift of life' will find hope within these pages as well. Isabel's and Anabel's life experiences are at once heartfelt and familiar. This is especially true for me when Isa describes how it felt waking up after a life threatening hemoptysis episode. "Hours later I woke up in the intensive care unit. I had no concept of time or where I had been. I could hear the pumping and beeping of the ventilator...I looked up and saw several bags of blood. Wow, my first blood transfusion. Cool!" (256)

Anabel and Isabel do not exaggerate and their stories reflect this. They simply write what they mean and mean what they say. Nor is it filled with overstated drama, like a few autobiographies I have read, portraying people overcoming the odds. Instead I can laugh at some pages that remind me of my own CF camp experiences and cry when I read about the tough decisions made when a loved one is seriously ill



and dying. Their family history and relationship with their parents and their brother are honestly written, in such a matter-of-fact way, it drew me more into their story.

From a reviewer's perspective, the book may be more suitable for mature readers. From a friend's perspective, I would have liked to have seen more written about their current lives as the memoir ended before Ana could write about her re-transplant. Overall I would highly recommend this inspirational and down-to-earth autobiography to my friends and family. "The Power of Two: A Twin Triumph over Cystic Fibrosis" is available on-line or at your local bookstore. A portion of the proceeds for this book go to cystic fibrosis research. ▲

In the interest of full disclosure: Katrina has known Anabel and Isabel for about 12 years. Katrina is 37 and has CF. She lives in Carlsbad, CA with her husband, Philip, who is 50, has CF, and had bilateral lung transplant in 2005.

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 that 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 arc 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 is March 28, 2008. The Exercise for Life scholarship application deadline is June 27, 2008. The Bonnie Strangio scholarship applications are due by June 13, 2008. Applications for the Scholarship of the Arts are 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.

GoodSearch.com Helps Raise Money For USACFA

Every time you use the internet, you can raise funds for USACFA. Go to: GoodSearch.com each time you want to surf the internet or find anything. They will pay us for every search by a user that designates USACFA as their charity of choice.

We just received another check from GoodSearch. Although it isn't lots of money, every little bit helps. Just use GoodSearch when you search the internet. Designate USACFA as the charity of your choice, and we get a few cents for each time you use it. This is a painless way to contribute to USACFA and we appreciate the help.

Years of Living Positively

By Andrea Eisenman

No doubt about it, laughter and thinking positively have kept me alive and kicking thus far. I attribute this to a few things. Mainly, my mom has always been a positive force in my life and has never let me give up. And when I am down, I will watch movies to take me out of my despair. I try for comedies or sitcoms, but anything that takes me out of myself will do. Another component is my love of animals, specifically dogs, and how much I enjoy their company. They make me smile and laugh when I never thought I could.

I will write about a time in my life when laughter did not come so easily and could be accompanied by lung bleeds. This period was the six years I waited for a bilateral lung transplant. While I was still working and had a social life, I still felt part of life – the world. I felt I had a purpose. It was hard going to work from 9-6, to come home, eat, exercise, go to sleep early and do it all over again. At the time, my lung function was barely in the 30s. I was so tired all the time all I wanted to do was sleep. On the weekends I did sleep and also tried to see a movie with friends and maybe a brunch if I was lucky. By being social, though, I was able to get out of myself and focus on others and their lives. I also had the pleasure of amusing, witty friends that kept me going. We all seemed to enjoy laughing at similar things and one another.

When I had to go on disability, I had to move back home with my mom. This meant I had to quit work temporarily and try to get my health back. I was so depressed about not being part of my social circle at my office as well as outside work. Moving out also coincided with breaking up with my boyfriend of five-plus years. Needless to say, this was not a happy homecoming.

I moved home with my dog, Sadie, who had made a name for herself in my Brooklyn neighborhood dog run. She was known as the dog that destroyed the apartment while I was at work. I had become friendly with other dog owners there and that was just another group of people I would miss. We all talked about our dogs as most playground moms yak about their toddlers. It was in that run that Sadie learned to play ball and Frisbee. Not just play them but master them to the point of throwing the ball back at me to continue the game. It was not uncommon to be watching television and suddenly have a stuffed and soggy toy thrust into my lap for a game of catch.

ANDREA EISENMAN AND HER LATE DOG, SADIE.

My boyfriend, Mark, and I had gotten Sadie after a long debate about whether to get a dog when we moved in together. I had expressed wanting a pooch as my biological tail was wagging. Mark had grown up with a dog and missed having one. We went to Bide-A-Wee and I saw her right away. She was in a cage with another dog and she was the only one who made eye contact with me. She also won the award for doing her "business" outside on a leash. The deal was sealed.

We took her home and realized that she had separation anxiety when we went to work. Quickly, we got her a walker during the day. Only to find that she would destroy the place thoroughly, before the walker came and after he left. She chewed apart a couch, three remotes for the TV, a camera, books, ate the garbage, drank half a bottle of Frangelico, and several other odds and ends. It was very stressful. But I connected with her and I had decided I would tough it out. I read books on dogs, hired a behaviorist and tried different strategies. Somehow, moving to my mom's and being home all day would solve the Sadie problem.

Sadie got over her separation anxiety to become the best dog I ever had. She demanded a lot but gave even more. She kept me busy, with throwing her a ball or a stuffed toy, for hours. She then came up with a game and invited anyone who happened to be over to play. She stood in a doorway and you had to kick a stuffed ani-

mal at her, trying to get it beyond her as a goal. She could catch just about anything. It was hilarious. And a great distraction to what was happening to my health and life as I waited for a transplant.

Sadie became a great distraction for my mom and me. It was almost as if she had a sense of humor. Sometimes when we walked her she would flirt with people on the street by shaking her rear at people. It was one of the funniest things. It really melted people who might have been afraid of her. And then, to really get them, she howled a funny Wooooo-woo at them and they inevitably came over to pet her. She loved the attention and this always made us laugh.

Sadie was also involved with chest physical therapy (CPT). After my inhalations, flutter, and my vest treatments, my mom would usually give me CPT for that extra clear feeling. Sadie knew and got right up on the bed with me. It was a human/canine conga line of CPT. While my mom pounded on me, I pounded on Sadie and we all laughed. She felt it was only right. She also was really supportive of a nap ANYTIME of the day. It was great to sleep with her as there were no judgments unless she wanted to play ball, but then she knew we always would play later.

We had moved to my mom's house in Long Island from Manhattan. Life was easier as we didn't have to walk Sadie four times a day, outside. We just opened the door and she did her thing. There were days, at that time, when I barely got out of pajamas. My lung function was in the teens and I was starting to lose hope I would make it to the transplant. But Sadie always was there with a smile and wagging tail ready to cheer me up.

Another classic trick of hers was that Sadie knew how to open the refrigerator. We soon learned this after she stole many meals, including half a turkey that we could not find for six hours. We thought she had eaten it but she had hidden it behind a couch pillow for later. My mom and I laughed so hard I could have foregone CPT for the day for all the coughing it brought on. When we found it, Sadie actually looked mad at us for taking it away from her. We learned to tape the fridge shut before leaving the house.

> "Sadie always was there with a smile and wagging tail ready to cheer me up."

Sadie was also involved with keeping me and my lungs fit before transplant. On the days I did not go to the gym to walk on the treadmill or swim a couple of laps, both wearing oxygen, we would walk on the beach. Sadie took this opportunity to play ball, romp in the surf and chase the seagulls. But she always looked back to see that my mom and I, and the oxygen tank, were not far behind. Then, at the halfway mark, we would just sit and look at the water and take in the beauty and peacefulness of waves breaking on the shore. (See photo at left.)

She really kept me going. When I finally had my transplant, I was in the hospital for 13 days. Due to immunosuppression issues and the fact that I had my chest opened almost two weeks prior, I was afraid that she would jump all over me when I came home. As I walked in the door, she started to try and lunge at me as I think she recognized me. But the weirdest thing happened, as she got up to smell me in the face, she looked perplexed. I mean she really had a confused expression on her as if she didn't recognize me. She got down and took another look. I looked the same, but I smelled completely different. Gone was the smell of pseudomonas lungs, and the constant coughing. There wasn't even an oxygen tube in my nose making a "chuh-chuh" sound. It didn't take her long to realize that it was still me, I just smelled different. She did, too, as my mom had her bathed before my arrival, to cut down on her 'smells'.

After that, Sadie and I were able to run on the beach together, swim in the bay, play ball to our hearts' content. Although we no longer did CPT together, we still took power naps on a daily basis. Once my mom put a pool in for both herself and me, Sadie sat on the porch watching us swim back and forth; we called her the lifeguard. And in between laps, she brought us a ball and we threw it for her to keep her happy. After all, we owed her a lot.

Sadie lived to a ripe old age of 11. We cherished her and appreciated her attitude toward life. She kept me positive at a very scary time. We went through so much together, I miss her very much. Of course, I did not know Sadie would die when she did; she had sudden seizures and never awoke. By that time, she was having trouble with arthritis and it was affecting her ball playing. She no longer loved to play for long periods but only about five minutes. Although I miss her and fondly remember our memories of her, I would not have wanted her to suffer. I am glad that she went quickly.

She was considered a rescue dog from a shelter. But really, she rescued us with her humor and grace. ▲

Andrea is 43 and is a Director of USACFA. She is the Executive Editor of CF Roundtable and Web master of cfroundtable.com. Her contact information is on page 2.

Two Heroes and a Team of Spikers: Priceless

By Kurt Robinson

Having cystic fibrosis and keeping a positive attitude can be tough at times. Especially when those times revolve around hospital stays, PICC lines, or a drop in my pulmonary function tests. I wish I could say that cystic fibrosis is always in the back of my mind and that I do not think about it on a daily basis, but that could not be further from the truth. The numerous medications, the daily-doubles of chest therapy using *The Vest®*, making sure my weight is kept up, and making it a point to exercise, are all things I would rather do without (with the exception of exercising). But I know the consequences of letting it slide. The benefits of staying on top of my health GREATLY outweigh the inconveniences of taking my medications and doing my therapies.

On a daily basis, and especially during the tough times, I have constant positive reminders of why I want to stay healthy and hospital free. Those reminders are my family, friends, and coworkers. I could write an entire novel about the positive influences that are present in my life, and maybe someday I will; but for now I want to give you a glimpse of a couple individuals and one collective unit who have made an impact upon my life.

Most of my previous articles in *CF Roundtable* revolve around at least one person who has made an impact upon my life. When someone asks me what is something that I enjoy doing, I often reply, "Spending time with my family and friends." A simple question and a simple answer.

Nearly three and a half years ago I met a man who has made more of an impact upon my life, both personally and professionally, than he ever will begin to realize. He and his company are responsible for raising more than $4.5 million for cystic fibrosis. In 2007 alone, more than $300,000 more will be added to this total. He works extremely hard, often answering my e-mails late at night and early in the morning within a couple minutes. Earlier this year, he was responsible for Barry Manilow performing a sold-out concert to benefit cystic fibrosis. But, if you were to meet him, he would speak of none of this. Do not be mistaken, he is proud of his accomplishments. Yet he is humble. He is Harvey Platt.

(L-R) HARVEY PLATT, KURT ROBINSON, AND BOB GILDER AT BOB GILDER'S PLATT GOLF CHALLENGE.

I had the pleasure of meeting Harvey in 2004 at his golf tournament to benefit the Cystic Fibrosis Foundation. After the tournament was over, I sent him a thank-you note. At the end of the note, I included my contact information and my email address. I never expected to hear from him, because I knew he was a busy person and because he is CEO of a successful company. Two days later, to my surprise, an e-mail popped up in my Inbox. It was from Harvey. In my thank-you note to him, I had mentioned that I am a huge Portland Trailblazers basketball fan and that I was looking forward to the upcoming season. In his e-mail, he mentioned he was a season ticket holder and would be happy to take me to a game sometime. I was like a little kid in a candy store! We agreed on a date to go to a game.

I was going to be graduating in about a year-and-a-half and I was contemplating what I was going to do with my life. As I told this to Harvey, he mentioned that if I would like to try it out with his company for the upcoming summer, to let him know. Several weeks later I contacted him and told him that, indeed, I would like to be an intern the upcoming summer. Thus began my career with his company and I have not regretted it one bit.

The most memorable part of that evening came on our drive back to my car after the game. My Grandma Ellen, who is the biggest Blazers fan I know, called to see how the game went. She could tell I was excited, and after I got off the phone with her I told Harvey all about her. He asked if she was able to attend a game. I replied with a simple "yes" and he said that he would like to give the two of us tickets to an upcoming game. Later that season, we were treated to a memorable experience, complete with a huge

"HAPPY BIRTHDAY ELLEN" message on the JumboTron at the arena, me being the honorary captain, and several family and friends getting to attend the game as well. My grandma still talks about that night.

Coincidentally enough, the second individual who has made an unbelievably positive impact upon my life, I met at a Cystic Fibrosis Foundation fundraiser as well. It was later that year that our friendship began to grow. I only get the chance to see him a few times a year due to his career as a professional golfer on the Champions Tour. Like Harvey, he is humble. His positive and good-natured personality radiates to those he surrounds himself with—his family, friends, and comrades on the tour. Luckily, he plays in an event in my home state, so I get to watch him annually. He always makes time to say hello and chat with me, even if he is focused and preparing for his round. However, Bob Gilder's path to cystic fibrosis is not one that you would wish upon anyone.

Bob's grandson was diagnosed with cystic fibrosis at a very young age. It came as a shock to his entire family, as it would to any family. Rather than sitting back and accepting that his grandson had been diagnosed with CF, Bob decided to attack it full-throttle and do something about it. He met with the CF Foundation and introduced himself to Harvey. Bob knew that he could enhance Harvey's golf tournament. The next year, Bob played in the event and he brought along some company. Several of Bob's friends on tour showed up as well to both raise more money for CF and to support their friend. Two years ago, the golf tournament was renamed to "Bob Gilder's Platt Golf Challenge".

Only a few weeks ago, Bob and I had lunch together. I had not seen him in several months, so it was nice getting a chance to catch up with him. We chatted and laughed and in doing so, he reminded me of why I want to stay healthy and happy—so I can enjoy more times like this in the future. Every time I see Bob, he always ends our time together with "if you ever need anything just let me know."

The last positive impact is not an individual, but a collective unit. More specifically, they are a team; a team of friends; a team of my friends. When I graduated from Western Oregon University a couple of years ago, I spent my final year as a student assistant with the women's basketball team. During this time, I got to know most of the other coaches in the athletic department. One of these individuals was head volleyball coach, Joe Houck. I often found myself down in his office talking about his team, WOU athletics, and life in general. Once I graduated, I kept in contact with Joe and attended many of his team's matches.

Before his season began in August, I told Joe that I would be attending even more of his matches this year and even hoped to make a couple road trips. After watching the first couple home matches, I was hooked. The team kept winning and I kept coming! I traveled with the team on one road trip and drove six hours to watch their final road trip of the season to Central Washington (which is where I am currently writing this article). The team was having a successful season and, as a fan, friend, and alum, it was fun to watch!

Midway through the season I approached Joe about his team getting involved with GREAT STRIDES, the Cystic Fibrosis Foundation's largest national fundraiser. I am the chairperson for the GREAT STRIDES walk where I live and I found it only fitting that a team that I had followed throughout the season become part of the event. Without hesitating he replied with an emphatic "We would be honored to be involved." The fundraiser is several months away, but I am already getting excited for it!

Watching the ladies play volleyball and their enthusiasm only encourages me to stay positive about CF and life as a whole. I want to be around for many years to watch them both compete on the court and see them succeed off the court after they graduate. They are always appreciative of me coming to watch (as they are of all their fans) and that only brings me back match after match to watch them compete. What started out as watching Joe's team play, evolved into many friendships with members of the team.

While I always enjoy writing in *CF Roundtable*, I get more excited for certain focus topics, such as this one. It is because it is something I can relate to and write about so passionately and confidently. As I stated above, there are so many more individuals and groups that have made such a positive impact upon my life. Harvey, Bob, Joe and the WOU volleyball team only begin to scrape the surface, but those are scrapes that I will cherish forever.

I consider both Harvey Platt and Bob Gilder heroes, angels, and friends. The WOU volleyball team is a group who will never realize the role that they played in my life, but the friendships and memories that they brought into my life will never be forgotten. Although they lead very different lives, Harvey, Bob, and the Western Oregon University volleyball team all have one thing in common: they are successful at what they do and they remain positive about it. By surrounding yourself with positive influences, it makes life that much more fun, enjoyable, and healthy.

Finally, a Happy 1st Birthday to my niece, Emry and Happy Birthday to my mom too! ▲

Kurt is 24 and has CF. He is a Director of USACFA. His contact information is on page 2.

POETRY CORNER

Black Licorice

By David Lee

(Remembering my donor family, after my double lung transplant)

Like a butterfly soaring through clouds and mist,
Like the biting cold of a frosty wind full in the face,
Like the tingle of a first kiss,
and the sorrow of a final goodbye,
Like watching a glorious sunrise from the top of a mountain,
or a magnificent sunset over a balmy tropical sea,
or counting millions of brilliant stars by the light of a full harvest moon,
Like nuzzling a baby with cooing caresses so close that you can feel its delicate heartbeat,
Like the sweetness of a warm stack of buttermilk pancakes
topped with freshly picked raspberries,
melting butter,
drizzled with real maple syrup,
and sprinkled with powdered sugar,
Like the silence after the last note of your favorite piece of music is played,
but before the applause begins,
when you linger suspended in the splendid performance,
All these "smooshed" together and rushing through my lungs
- this is what breathing is like for me.
Like black licorice candy, both bitter and sweet
- this is what breathing is like for me.

David is 45 and has CF. He had bilateral lung transplant in 2001. He lives with his wife, Sandra, and their 9-year-old twins in Yardley, PA. He is a TV/film/media producer and creative director.

2007 NORTH AMERICAN CF CONFERENCE *continued from page 1*

teers with CF who received the drug over those who received placebo. Gilead Sciences also announced an Early Access Program (EAP) for those patients with severe disease and limited treatment options, while the drug awaits an FDA decision on approval. To find out more about this program go to EAPforCF.com.

Another company, Inspire Pharmaceuticals, presented an update on enrollment for their TIGER-1 trial of denufosol, an inhaled drug designed to activate an alternative ion channel and improve respiratory symptoms. This is a year-long trial so results will not be available for some time. However, to speed the drug development process, the company announced plans for a second trial, TIGER-2, to begin in early 2008 in the United States. Both trials are targeted at individuals with milder lung disease. Ask your CF Care Center if you are interested in learning more about these trials.

The plenary session on the second day of the conference was given by Dr. Felix Ratjen, a respected physician and scientist from the European CF research community, who now practices in Canada. He spoke about new drugs being researched. He recognized that many trials are slowed by the need for volunteers. Dr. Ratjen explained that the need for volunteers is greater than ever before. In 2003 only 500 volunteers for trials were needed but an expected 6,000 volunteers will be needed in 2009. Speakers throughout the second day discussed ways the CFF is trying to bolster clinical trials participation with efforts like information pamphlets and a toll-free clinical trials hotline. There were also sessions that discussed Quality Improvement Initiatives at a variety of CF Care Centers. The sessions provided an opportunity for CF Care Center team

members to learn from the successes of other Centers.

The last day of the conference began with roundtable discussions. Conference participants had the chance to break into one of 100 interest groups and delve into a range of topics; including the latest news from the research bench, CFTR structure, and inflammatory components in the airway. Some roundtable groups focused on care, inviting staff from different care centers to compare notes on a wide variety of issues such as sinus disease and CF-related diabetes. There were more formal sessions where data from studies was presented. One such study involved results from ongoing CF newborn screening programs. There were strategy sessions to help new programs improve their ability to detect infants with CF before serious damage is done to their lungs and to help them have much healthier lives. There now are 40 states that conduct newborn screening for CF.

The last plenary session was related to the CFF's Quality Improvement Initiative. Dr. Michael Boyle, the director of the Adult CF Care Center at Johns Hopkins Hospital in Baltimore, Maryland, spoke about the opportunity provided by the CF Care Center network to improve the health of people with CF across the nation. Dr. Boyle described how the information collected by care centers and placed into the CFF Registry was studied to find the CF Care Centers with the best nutritional or pulmonary ratings. Those centers were then visited and their treatment policies and philosophies were carefully analyzed.

From this analysis, 10 suggestions that other CF Centers might use to improve outcomes in their own patients were formulated. Dr. Boyle discussed the remarkable improvements that two CF Care Centers made by instituting these changes. Dr. Boyle's speech was certainly one of the best, if not *the* best, plenary presentation in the history of the CF conference. He gave concrete examples of how CF Care Center team members could find new ways to help patients and deliver quality care. The session ended with 3,000 attendees feeling renewed and energized to either continue to improve the research they are doing in their labs, or to deliver the best care possible to their patients. ▲

In Memory

Susan L. Kelly, 55
Queen Creek, AZ
March 31, 2007

Immediate family members may send in the names of CF adults who have died within the previous year for inclusion in "In Memory." Please send: name, age, address and date of death.

Send to:
CF Roundtable
PO Box 1618
Gresham OR 97030-0519.

E-mail to:
cfroundtable@usacfa.org

Benefactors

BRONZE

Anonymous
Darleen Boynton
Theresa DeWolfe
David Ebacher
Edward Fleischman
Mary E. Furey
Eileen Gallagher
Nancy T. Geigerich
Jean M. Hanley
Cathleen Hoolapa
Carroll Jenkins
Mr. & Mrs. Klaus Miodov
Kim Nunnari
Merle & Lois Pittman
Roger Postelthwaite
Sondra Rabinowitz (in honor of Pammie Post receiving the Jacoby Angel Award)
Rose City Model T Club
Maryjane Sanchez
John & Nancy Stanley (in memory of their son John Alan Stanley)
Leslie Sternlieb
Florence Tillman
Janet Tillman
Laura Tillman
Martha Weber
Daniel Winoker
Jay M. Wright
Helen Young

GOLD

Dean & Diane Chrones

PLATINUM

Helen Eisenman
Nancy Marcuz Wech

Those who give $50 or more in a year will be recognized as Benefactors, unless they request anonymity. The categories are: $50-$249 Bronze Benefactor, $250-$499 Silver Benefactor, $500-$999 Gold Benefactor, $1,000 and over Platinum Benefactor. Donations over $10 are tax deductible. Please make checks payable to USACFA, Inc.
Send donations to: **USACFA, Inc., PO Box 1618, Gresham OR 97030-0519**

TRANSPLANT TALK

My Third Anniversary

By Paul Feld

Always take care of yourself, and never take your health for granted. This is the lesson I learned in the past 50 days. Since my transplant three years ago, my post transplant quality of life has been very good, and I have been extremely blessed. Sure, there have been some bumps in the road, both big and small, but I've been able to live life to the fullest. This year had been especially trouble-free.

In my clinic visit just two weeks prior to my anniversary, I had asked my pulmonologist to remove from my chest the port that was implanted almost four years ago. It hadn't really been used all year, and I was feeling great. He said they could do it, but my FEV_1 numbers had been down about 10% overall in three consecutive visits, and he was mildly concerned. He suggested a bronchoscopy on the date of my third anniversary, October 23, 2007. Since my lung function was still about 120% of expected levels, and I was feeling just fine, how could I argue? Besides, I've had about 25 bronchoscopies since my transplant anyway, so what's one more?

So began the month from hell. For me, my bronch on my anniversary date had gone just fine. As usual with my bronchs, they give me *Versed* as my anesthetic and my short term memory from the time of injection just disappears from my brain for the rest of the day. This time around was no different for me. My wife, Kristi, saw things differently, however. I was not asking the same questions over and over again, and I just wanted to sleep. Even my appetite was minimal, when I'm typically scarfing down anything they put in front of me.

When I got home, I went to bed, and slept and slept and slept. Generally when I have an early morning bronch, I live the day, forget the day, and am ready for work at 7AM the next morning. I've probably done this routine 90% of the time. This time around, however, I was extremely tired, and just wasn't feeling normal. I did get up and worked my typical day, but I did not spring back to life as I usually do. The next day was even worse. I began running a fever that got worse as the day went on. I would take some *Tylenol* for some temporary relief, but a few hours later, it would return. I was just miserable, and endured this for three more days.

On October 29th I had a chest x-ray, which revealed pneumonia in my left lung. That same day a preliminary culture return from my bronch showed I had a staph infection in my right lung. Fortunately for me, the staph was penicillin sensitive, and my physicians immediately started me on IV therapy. So for the first time in over a year, my port-a-cath was accessed for a real problem.

PAUL FELD

The IV therapy did not seem to help much. My fevers continued for several more days, more pronounced at night, but my physicians insisted we were on the right track. I just needed to let it play out. I returned to work on November 5th, feeling significantly better, but still with the occasional mild fever at night.

The next day we had unusually nice weather in town, and I decided to walk a few hundred yards and pick up a sandwich for lunch. About half way to my destination, I saw 50 yards of free sidewalk, and decided I'd jog to the end. I'm usually jogging 2-3 miles a day anyway, but I had missed about 10 days due to my illness. This was a quick opportunity to start to get back on track. I zipped down the sidewalk to the end, and found myself breathing extremely hard for a jog that short.

Suddenly, I got this sensation that I had not had in three-and-a-half years, and it was not a pleasant one. Anyone who has had frequent hemoptysis (coughing up blood) knows this feeling. I sat on the curb and waited a few seconds for the inevitable. A quick, short spit to the ground verified my fears. For the first time, my new lungs were bleeding, and thoughts of my pre-transplant life filled my head. This time, however, the center of my chest felt extremely painful, and every breath hurt. After thinking of ways to calm and settle myself down, I was able to walk back to my office at work. Every breath still hurt, and my chest was pounding. I called my transplant coordinator immediately, who got my physician on the line. He said I had two options: Get to the hospital for immediate check-in,

> "There have been some bumps in the road, both big and small, but I've been able to live life to the fullest."

or come by his office for a chest x-ray and immediate evaluation. I chose the latter and got an x-ray within 30 minutes, and got to see him within 45 minutes. The diagnosis was clear – I had a left lung collapse.

He verbally prepared me for the next 24 hours, and got me a room in my favorite hospital. Coincidentally, it was the very same room I was in post-transplant three years earlier. I felt like I was reliving the past. I lay in bed for the first hour in my room, and re-lived the last three years. I realize what an extremely lucky man I have been. I had done things in those three years that I had not done in the last 30 years. I've grown closer to God, my family, and my friends, and I've done all this while feeling great. I had memories of running the track with my friend, Isa, this last summer. We'd walk the straight-away's and sprint the curves over four laps. How great that felt, both the exercise and camaraderie. Now suddenly, I had a collapsed lung, and visions of a downhill spiral ran rampant in my mind. What will be, will be, I thought, and the future is in His hands.

My chest tube was put in that night. Ah, the memories of chest tubes post-transplant. None of them are fond memories. They hurt going in, they hurt being in, and they hurt the most being removed. Percocet became my *best friend* for the next four days, as my lung tried to refill the space it once occupied. On the fourth day my chest tube was pulled, and after a few hours, I was sent home 10 pounds lighter, with a sincere verbal dialog about not doing anything to stress my precious gift for the next four weeks – no running, no jogging, no thinking about jogging; you get the idea. I needed to hear this, because I am who I am, and my docs know me. If they are on the fence with anything, I'm jumping over it.

The last couple of weeks I've been in recovery mode. I've found out my chest tube probably should have stayed in another day, as I have a pocket of air/fluid behind my left lung that will take weeks to dissipate, and it really makes a chest x-ray look bad. I'm feeling much better again, and can't wait to start exercising like normal.

I now look at this whole experience as a reminder of the wonderful gift I received three years ago; this gift that turned a weak, skinny, breathless man into a strong, confident, vibrant human being. Someday I'll return to the shriveled being I once was, but this wonderful gift continues to extend my existence and quality of life, and I will be forever grateful to my donor and his family for their decisions in October, 2004. ▲

Paul Feld is 50 and has CF. He had bilateral lung transplant three years ago. He is a Director of USACFA and is the President. His contact information is on page 2.

Information from the Internet...

Compiled By Laura Tillman

This issue brings a potpourri of articles from the Internet

NEWS RELEASES

Gilead Announces Detailed Results of Phase III Study of Aztreonam Lysine for Inhalation in Patients With Cystic Fibrosis

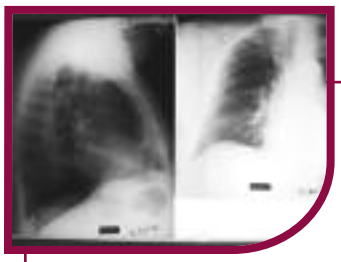
Gilead Sciences, Inc. announced detailed results of its Phase III AIR-CF1 (CP-AI-007) study of aztreonam lysine for inhalation, an investigational therapy in development for the treatment of people with cystic fibrosis (CF) who have pulmonary Pseudomonas aeruginosa (P. aeruginosa). In this study, a 28-day treatment course of aztreonam lysine improved respiratory symptoms as assessed by the Cystic Fibrosis Questionnaire-Revised (CFQ-R), a patient-reported outcome (PRO) tool. Aztreonam lysine also improved pulmonary function in this study, as measured by relative improvement of forced expiratory volume in one second (FEV_1), a standard measure of lung function.

http://salesandmarketingnetwork.com/news_release.php?ID=2020957

Vertex Potentiator Trial Underway; Corrector Slated to Begin Trials by Year's End

The Vertex compound known as VX-770 has entered Phase 2 clinical testing and is in the process of enrolling 36 adult volunteers at more than a dozen care centers across the

Continued on page 35



A DEEP BREATH IN
The Power of...

By Debbie Ajini

We all have heard the phrase "The Power of Positive Thinking". But what does it mean, really? It does sound a little hokey. It can conjure up images of new-age groups sitting in a circle chanting and burning incense. However, there is truth to it and I have learned it firsthand.

As anyone with a chronic or terminal illness knows, we go through the "What if" stages. What if this drug doesn't work? What if I don't get better? What if I get worse? What if…? What if…? They can be endless. I have found the challenge to be in saying it a different way. My body only knows what my heart and mind think. THAT is what is true. What if this new drug works? What if I gain four pounds in a month? What if I can walk farther tomorrow?

While it is probable that I can't cure myself just by positive thinking, it does have the power to change my energy and thoughts to a place that promotes healing and well being. When I have had a long day and I am tired and the "What ifs" start, I try to redirect myself to accept that I might feel better tomorrow. Or I will focus on what I was able to do that day. I always try to end the day with a positive thought.

When I can redirect my thoughts to positive ones, I can't think of negative ones. At least, not at the same time. It is impossible. As impossible as eating and breathing at the same time or walking and running at the same time. You have to pick one. Our mind goes where we tell it and where we let it, for better of for worse. Now, please understand, sometimes it takes me a long time to get to the positive side. It has taken me hours, days, and longer. But eventually I get there. And I figure as long as I keep trying to get out of the pattern, to the other side, is to be successful.

I am sure you can think of people who are ALWAYS positive and upbeat or ALWAYS negative. If you look at their lives you can probably see how it tends to follow their disposition. Is it the actual events that are good or bad or how we perceive and react to them? Because there have been, and always will be, positive thinkers who get hurt, who have bad things happen to them, and who die. So doesn't that prove it's not all it's cracked up to be? The phrase "Everything happens for a reason" does offer some sense of comfort but certainly no answers. It is about taking each day, each experience, each moment and putting it in a positive light. Positive thinking is a hard thing.

When I had a massive hemoptysis, I just stood there, coughing up mouthfuls of blood. I was scared. I was afraid I would die right then. After a few minutes, after an ambulance had already been called, I made a switch in my head. I chose to go from thinking "Oh no" to "This is not going to kill me and I won't let it". And I could physically feel myself straighten up and get ready to do battle against this, so to speak. And in a few more minutes the bleeding slowed and when the ambulance came it was over. Did my change in thought help? I don't know. My body could have just finally been able to clot where I was bleeding. I will never know. But I DO know it didn't hurt to try to change where my mind was going at that moment. After that initial burst of positive thinking I was scared again. For many months I was afraid it would happen again. I was afraid it would be somewhere that I had less control, less help. I had to work literally minute by minute in my head to keep turning my thoughts around. And when I find that same fear creep up again, I do the same thing.

DEBBIE AJINI

I see positive thinking as another therapy I do everyday. Just like all my other therapies, I don't like doing them sometimes, some days I forget, some days I skip them; the same is true with positive thinking. Sometimes I suck at it. And then I will have a moment where I realize I need to rein it in and shift my focus. I work at it. It takes a lot less energy to lie in bed and be sad then it does to get out and carry my oxygen around Target. But I am sure you can guess which makes me feel better in the long run. And I have found the more I can feed that part of me that gets filled with positive thinking the more reserves of it I have when I need it. So when I am having a particularly hard time, I can look back on the times I made it through to the other side. I can have a place that I draw on when I am really unable to go out to Target or up the stairs.

In a more literal sense of positive thinking, I have read some great books about it and healing (see my column in

TILLMAN *continued from page 33*

the Summer 2006 issue of *CF Roundtable*). I get inspirational e-mails from various sites; my favorite is www.dailyom.com. I have also found being around other positive thinkers helps. I try to laugh a good full belly-busting laugh every day. It is impossible to do that and have a negative thought! And if I am in a real funk, I know I need to go see my psychologist. Just getting all the "crap" out of me, by talking, helps make room for the new positive stuff I want and need to focus on. Positive thinking is just one more tool I can use to manage my health and my life. As with anything worthwhile, it takes lots of practice.

I have used quotes in many of my past columns and this one is no different. I leave you with these…

"A man is but the product of his thoughts what he thinks, he becomes." Mahatma Gandhi

"Positive anything is better than negative nothing." Elbert Hubbard

"It takes but one positive thought when given a chance to survive and thrive to overpower an entire army of negative thoughts." Robert H. Schuller

"Staying positive may not have an immediate effect on your situation, but it will likely have a profound and instantaneous effect on your mood and the quality of your experiences. In order for positive thinking to change your life, it must become your predominant mind-set. Once you are committed to embracing positive thinking, you'll start believing that everything that you want is within your grasp."▲

Reprinted from DailyOM- Inspirational thoughts for a happy, healthy and fulfilling day. Register for free at www.dailyom.com.

Debbie is 37 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.

country. The VX-770 trial studies the safety, tolerability and absorption rate of VX-770. The compound, which belongs to a category of compounds called CFTR potentiators, is believed to partially restore CFTR protein function and increase the probability that the CFTR channel is open. VX-770 may allow for increased chloride transport across the cell surface, alleviating a fundamental problem in cystic fibrosis. The previous Phase 1 trial, completed in 2006, showed that the potential drug could achieve the expected levels in the blood. In addition, Vertex recently selected a second compound for development. The compound, known as VX-809, is expected to begin clinical development by the end of 2007. VX-809 is part of a class of compounds known as "correctors," which help the defective CF protein move to its proper place in the cell.

http://www.cff.org/aboutCFFoundation/NewsEvents/index.cfm?ID=7673&TYPE=167

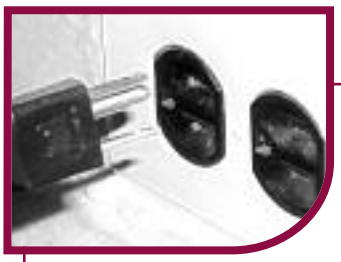
Unexpected Bacteria Identified In Cystic Fibrosis Patients

Molecular technology developed by a University of Colorado at Boulder professor to probe extreme life forms in undersea hydrothermal vents has been used to identify unexpected bacteria strains in the lung fluid of Denver children suffering from cystic fibrosis, findings that may lead to more effective therapies. Instead of standard culturing techniques, researchers used nucleic acid gene sequencing to rapidly detect, identify and classify pathogens found in the lungs of cystic fibrosis sufferers. More than 60 species of bacteria in samples of 28 cystic fibrosis patients were identified. Thirteen samples contained bacteria that are not routinely assessed by culturing. The presence of the unexpected bacteria may help explain cases of unidentified lung inflammation and the consequent failure of patients — primarily children — to respond to standard treatments. "The results show molecular sequencing is a more effective, faster and far less expensive way to assess airway bacteria than routine clinical cultures and better identifies targets for further clinical evaluation," said Pace. About 80 percent of pathogens identified in cystic fibrosis patients using the novel gene sequencing technology belong to three common bacterial groups, including the group that causes strep infections. But the remaining 20 percent were from unexpected bacterial strains that would not normally be cultured in cystic fibrosis lab tests. Pace said that the molecular method involves isolating and amplifying bacterial nucleic acid samples from the lung fluids, then sequencing them to census individual pathogens by where they fit on the phylogenetic, or family, tree.

FYI

Cystic Fibrosis Pulmonary Guidelines. Chronic Medications for Maintenance of Lung Health. Patrick A. Flume, Brian P. O'Sullivan, Karen A. Robinson3, Christopher H. Goss, Peter J. Mogayzel, Jr., Donna Beth Willey-Courand, Janet Bujan, Jonathan Finder, Mary Lester, Lynne Quittell, Randall Rosenblatt, Robert L. Vender, Leslie Hazle, Kathy Sabadosa, and Bruce Marshall. Am J Respir Crit Care Med. 2007;176:957-969.The Pulmonary Therapies Committee, established by the Cystic Fibrosis (CF) Foundation, has issued evidence-based recommendations regarding long-term use of medication for maintenance of lung function in patients with CF. Based on systematic and Cochrane reviews, the guidelines discuss the use of aerosolized antibiotics, dornase alfa,

Continued on page 40



UNPLUGGED...
With Mike Hyland

By Richard De Nagel

Hello everyone, and welcome back to another exciting edition of "Unplugged." I hope everyone had a good holiday season and a happy new year. I am shocked another year has gone by. I thought I had gained some weight over the holidays, but I got all backed up, which is no fun. After all the laxatives kicked in I actually lost weight. I knew it was too good to be true and I had way too much gas anyway. So that was my welcome to 2008!!

I am, as usual, very excited to introduce our next guest. He talks about sex, strippers, and rock and roll; what more could you want! He hails from the state of Texas and has a great perspective on life. He is another one of those transplant people, and even went in for another round a few years later. He is quite a fighter. Beyond that, he is a great guy. I am happy to introduce Mike Hyland.

1) Name Mike Hyland

2) Age 41

3) Where do you live? Does that have any affect on your health?

I live in Dallas, TX. I don't notice any ill effects from living in a big city. The altitude is low and the weather is good enough I can work out year round outside.

4) When were you diagnosed with CF?

Shortly after birth, in 1966. I received two new lungs in 1997, and a new kidney in 2006.

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

For my lungs and CF I go to St. Paul/UTSW hospital in Dallas. I've seen Dr. Randall Rosenblatt for about 15 years now; he's a great guy. There have been times when he's come into my hospital room just to watch basketball with me.

MIKE HYLAND AND DR. DAN MEYER, MIKE'S LUNG TRANSPLANT SURGEON, RUN A MARATHON.

6) How would you describe your health now?

Excellent. My FEVs are 100%. I ran a marathon a few years ago and haven't reached that peak of fitness since; but I do something physical most days.

7) What type of Chest Physical Therapy do you do? Are you compliant with it?

I used to use the vest three times-a-day, rain or shine. Post transplant, I have not had to do mechanical therapy, but I do an inhaled antibiotic for ten minutes twice a day to prevent pneumonia.

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

I had done breathing treatments, chest therapy and enzymes since I was a baby. I used to sleep in a mist tent, too! But when I went to college at age 18 was when my lungs really started to deteriorate. I had always been very active, but I started having problems walking across campus or up stairs.

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

I've been listening to "the Police" a lot lately. We just saw them in concert. I play piano and keyboards in three bands, so I also listen to the songs I need to learn. My favorite CD is R.E.M.'s "Life's Rich Pageant". I like to dig around the half price CD store and look for '80s college/alternative bands.

10) Are you working? How is that going?

I worked as an electrical engineer designing computer chips for about 12 years, but I stopped working five years ago. At the time I was having bad rejection problems, and spent 85 days in the hospital over that year. Trying to keep up with work was becoming a real problem. I'm a lot healthier now without it.

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

I am a Christian, and so believe Jesus was the Son of God. I really struggled with this at times, probably because my health was so bad. How could God allow such things as CF? But I realized that trying to make a decision about the truth (or not) of Christianity is impossible without studying the Bible. Sort of like taking a chemistry test without looking at the text book. So I started going to church and joined a Bible study even though I wasn't sure about it. I also spent a little time learning about some of the other major religions. I've probably put more thought and study into this one question than any other.

12) What are your hobbies? Does CF interfere?

I play piano for two contemporary Christian bands. Our bass player is a respiratory therapist from the hospital; I recruited him while I was there. It is great fun, and I get to feel a part of our worship services. I also play in a cover band that plays coffee shops and parties. Occasionally I'll get ill and have to skip a performance. When I get sick, it happens really quickly, like in just a few hours. Pre-transplant, with work and all the vest/breathing treatments every day, I didn't have time for anything like this.

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

I've been married for 17 years. Delonna and I met at Purdue University, when my health was already lousy. Somehow, she saw through that to see what a great person I am (Ha! Ha!). CF and transplant have been a large part of our lives. She supports us now with her job and insurance, and is always ready to make a trip to the hospital at the drop of a hat. She is an awesome person.

14) What is your most embarrassing CF moment?

I had a colonoscopy not long ago. When I was still loopy from sedation, I told the hospital staff that my wife was a stripper and that we moved to Dallas because the pay was better. My parents were there, too. I don't remember this at all. The staff was quite surprised and they look at my wife a little differently now.

15) What gets you through the tough days?

I've got family and friends who really help me out. I know I can ask them to take care of me when I need it.

16) What do you hate most about CF?

Ugh - the gasping for air. I'll never forget that. Now, post-transplant it is the occasional GI blockage. That can be immensely painful.

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

My favorite movie is "The Blues Brothers". It is a riot and I sing along (badly). I like comedies such as "The Office" and "My Name is Earl".

MIKE AND DELONNA HYLAND

18) Do you have kids? Want them?

No kids, just a chow dog, Kona. I do have two nephews nearby (ages six & 11); I teach piano lessons to them, so I see them at least weekly. When I get tired of them, I can send them home.

19) What do you look forward to?

Well, heaven is something that I don't think any of us can really comprehend. So that is intriguing. I'm just not ready to go yet! I've had three CF/transplant friends die this summer. We all know that our time is limited. That doesn't stop me from making long-term plans, but in the meantime, my wife and I love to eat at new restaurants, listen to live music and meet new people. There is room for enjoyment every day.

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

I would never wish this on someone, but when I look at all the experience I've had because of CF, it is hard to say I wish I'd never had it. Look at all the awesome people I wouldn't have known. Without CF, by age 41 my health could have been just as bad from some other problem.

21) Tell us about your friends?

I hang around a lot of musicians. They all have girlfriends or else they'd be homeless. I have great friends going back to when I was young whom I still keep in touch with, and my brother is a great friend, too.

22) What is your favorite color?

Black. I'm going to paint the bedroom black next time my wife goes out of town.

My wife said, "No way", to the black bedroom. So, favorite color, please put my answer as: Old Gold and Black (Go Boilermakers!)

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

There are several of us CF patients post-transplant from St. Paul in Dallas that meet regularly. Usually we eat a lot and make each other laugh. It is awesome to be able to learn from each other since we have many experiences in common. I also speak to pre-transplant recipients at my hospital about my life post-transplant.

Continued on page 39

POETRY CORNER

Faith...from Amen to Zen

By Nahara Mau

Amen.
appreciate all
accept angelic assurance
adopt affirmations
attain authentic awareness
act absolutely alive
assume awakened attitude

breathe
believe blessings
become balanced beings
blossom boldly
be brave

change
connect consciously
consider consequences constantly
choose courageous challenges confidently
clarify communication
create clear convictions
celebrate community

dream
devote daily
desire divine depth
develop daring determination
discover drive

evolve
exude enthusiasm

engage everlasting essence
express emotions
embrace essential energy
expand experiences
encourage enlightenment
extend exhalation

flow
fortify faith
feel forgiveness
face fears fiercely
find fulfillment
fuel forward

glow
glorify God's gifts
grab groovy gusto
gather gratitude

hope
have harmony
heed heavenly help
heal hidden heart
honor heroes

imagine
ignite intuition
invite insightful illumination
integrate inner ideals
implement inspired ideas
increase intention

juggle
journey joyfully

karma
keep knowing kingdom
kindle knowledge

leap
love limitlessly
live life learning lessons
listen lovingly
linger longer

mentor
marvel miracles
monitor metaphysical messages
master mindfulness
manifest mission
move mountains

nurture
notice nature newly
nourish necessities
nix neurotic naysayers
need nothing now

Om
open options
orchestrate opportunities
overcome obstacles

pray

praise purpose
persevere path passionately
purify potential patterns
pursue precious passions
progress patiently

quest
question quietly

revivify
risk rejuvenation
remove rascally resistance
recognize revealing reflections
remember rituals
reach resolutions

strive
spark senses
survive significant situations
share synergistic sojourn
suspend suspicions
seek sacred spirit

thrive
treasure time
transform toward truth
transend tests
trust totally

unlock
unleash uniqueness
unfold unlimited universe

understand unity

validate
visualize vitality
vanquish victimhood
venture valiantly

wonder
watch world wakefully
worship wholeness
work with willingness
welcome wellness

x-amine
x-pire x-isting x-pectations

yearn
yield yes

Zen.

Author's note: This is a revised poem that originated two years ago, when Breathing Room requested entries about how faith plays a role in our lives, particularly in regard to our health challenges and spirituality. The website is: www.thebreathingroom.org.

Nahara Mau, age 50, lives with her husband and daughter in Fremont, CA. Nahara has CF and has had bilateral lung transplant. You may reach her at: nahara@gmail.com

UNPLUGGED *continued from page 37*

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?

I've been reading *CF Roundtable* since the beginning, and always found it very emotional to read. I'd never really spent any time with anyone with CF. Since then I've always tried to learn as much as I could about treatment possibilities, and when I became eligible for transplant, switched my focus to that. I've been very compliant since about age 22. From age 18-22, not so much. As for self-image, like many folks, I never talked much about CF when I was younger. But now, everyone knows that I've had a transplant. It is my job to show them that transplant works.

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

Night. I'm the kind of guy who doesn't want the day to end.

26) What did you think transplant would be like? Were you scared?

By 1997, my lungs were so bad; I was just excited about the possibilities post-transplant. I really wasn't worried about it at all.

27) Was it as difficult or more difficult than you imagined?

I have an interesting perspective on this now, since I had a kidney transplant in 2006. When my lungs were transplanted in 1997, it was difficult, but I could immediately breathe so much better that I didn't care what hurt or what I looked like or anything, I just felt great. When I had my kidney transplant, there was no immediate "life is so much better" phase. I just did not have to do dialysis anymore. So in that sense, recovery from the kidney transplant was actually more difficult.

28) What has changed in your

Continued on page 40

life since your transplant?

My physical capabilities are far above where they were pre-transplant. When I started running, my lungs were great, but my legs were so weak from being sick for years. It took a long time to build up so that I could run a few miles. And since Rich wants to hear about my sex life (blame Lisa Steiding in the last "Unplugged" for that), let's just say that I don't have more sex (after all, I've been married 17 years now), it just is easier. Now I don't see black spots and feel like I'm about to pass out afterwards. :)

29) Did it change your outlook on life?

I've usually been a pretty optimistic guy, and that hasn't changed. The post-transplant survival statistics don't look all that great (50% live 5 years), but what were the odds of my living this long to begin with? Very small. I've always had many things that I wanted to accomplish, regardless of my health, and that is still true. I just have more time for them now - and (this is important!) I can't lose sight of my goals! Just because I am healthy now, I can't put off my goals for a later day like too many people do.

So that is Mike, who no longer sees black spots!! I couldn't believe he ran a marathon, but he sent in a photo as proof. Mike is someone who is very easy to talk to and has a great attitude about life. Just to clarify, from this interview, it would seem that I am obsessed with sex. But *he* brought up the stripper topic. I will let you decide. I was merely bringing up sex after Lisa, from the last issue, pointed out her increased sex drive post-transplant. I was curious if others have had the same experience. If it was true I was going to chat with my doc about it. I never brought up strippers. In response to the question about his most embarrassing experience with CF, he raised the topic about his wife. (She is not a stripper.) So where's *Mike's* mind? It is no wonder she won't let him paint the bedroom his favorite color. Back to me, I am just happy when I don't pass gas during sex. That's a good way to ruin the mood.

One of the most challenging aspects of CF is that I am alone with it most of the time. I go through days and days without seeing or talking to someone who understands what I go through. When I do get the chance to connect with someone with CF experience, it lifts my spirit in a way nothing else can. Case in point: my conversation with Mike turned me around. I had been in one of those funks that I've described before - being sick, not wanting to do my treatments, tired of all the crap with CF - and after our conversation I felt better. I struggle with having CF all the time and over the years I have looked for ways to deal with it. One of the best ways for me has been to connect with someone else who has CF. Thanks, Mike. You're an amazing guy, and very easy to talk to.

Also, another way to remind myself that I'm not alone is through reading. I have had a subscription to *CF Roundtable* since 1993, or so, and I read each issue cover to cover. From time to time, a good book comes along, like "The Power of Two: A Twin Triumph Over Cystic Fibrosis," written by two sisters who have CF. It is an amazing read and the authors, whom I have met, are great. From here on out they will be known as the Famous Ana Stenzel and Isa Stenzel Byrnes. The point is, again, I can identify with them and relate to their experience, and you might, as well. When I find something that helps break this isolation, I feel better. I also end up taking better care of myself and using my Vest more; all the things that make me and my life better. And I remember I am not alone. ▲

Rich is 39. He has CF and is a Director of USACFA. His contact information is on page 2.

TILLMAN *continued from page 35*

hypertonic saline, oral corticosteroids, inhaled corticosteroids, oral nonsteroidal antiinflammatory drugs, macrolide antibiotics, inhaled bronchodilators (including beta-agonists and anticholinergic medications), and oral antistaphylococcal antibiotics. They also review still unanswered clinical questions. The authors have reviewed and evaluated the evidence supporting the use of chronic medications used for the maintenance of lung function in patients with CF. They have developed recommendations based on the quality of the published evidence and the estimate of the net benefit demonstrated within those publications. The authors indicate that they recognize the limitations of their review, due particularly to a lack of data regarding therapies in children less than 6 years of age. This document should be viewed as a guideline regarding CF care. The introduction and use of specific medications will depend on the individual patient, their social situation, and parental or patient preferences.

http://www.medscape.com/viewarticle/565955

TREATMENTS

New pulmonary therapies for cystic fibrosis. Ratjen, Felix. Current Opinion in Pulmonary Medicine. 13(6):541-546, November 2007.

Improved knowledge of the molecular mechanisms underlying cystic fibrosis has led to a wide spectrum of new treatment approaches. This review addresses recent therapeutic strategies that either target the underlying defect

or early steps in cystic fibrosis pathophysiology. While gene therapy does not appear to be a therapeutic option in the near future, cystic fibrosis transmembrane regulator pharmacotherapy is currently being developed as an alternative to reduce cystic fibrosis transmembrane regulator degradation or improve its function. Two drugs that increase chloride secretion via an alternative chloride channel, Moli1901 and denufosol, have been shown to be safe in clinical studies that also suggested clinical efficacy. Osmotic therapy may be an alternative approach to increase airway surface liquid and is being studied as an early intervention strategy. The spectrum of treatments for cystic fibrosis lung disease is rapidly increasing. While clinical efficacy for most of the compounds still has to be proven in large clinical trials, there is considerable hope that cystic fibrosis therapy will move from addressing the downstream sequelae of the cystic fibrosis transmembrane regulator defect to a more causal approach in the near future.

http://www.mdlinx.com/PulmonologyLinx/newsl-article.cfm/2000438

Oral anti-pseudomonal antibiotics for cystic fibrosis. T Remmington, N Jahnke, C Harkensee
Cochrane Database of Systematic Reviews 2007 Issue 3

Treatment of *Pseudomonas aeruginosa (P. aeruginosa)* lung infection is of great importance in managing cystic fibrosis lung disease. Oral anti-pseudomonal antibiotics which are as effective and safe as intravenous or nebulised antibiotics would improve the quality of life of people with CF due to ease of drug administration and the avoidance of hospitalisation. We found no conclusive evidence showing an oral antibiotic regimen to be more or less effective than an alternative treatment for either exacerbations or long-term treatment of chronic infection with *P. aeruginosa*. However, the evidence available was limited as there were only 6 trials with 282 participants. Also the trials were very different in terms of design, drugs used, duration of treatment and follow-up and outcome measures. Until results of adequately-powered future trials are available, treatment needs to be selected on a pragmatic basis, based upon known effectiveness against local strains and upon individual preference.

http://www.mrw.interscience.wiley.com/cochrane/clsysrev/articles/CD005405/frame.html

---

Anti-inflammatory approaches to cystic fibrosis airways disease. Balfour-Lynn, Ian M. Current Opinion in Pulmonary Medicine. 13(6):522-528, November 2007.

Therapy aimed at combating excessive lung inflammation should benefit patients with cystic fibrosis. This article reviews anti-inflammatory strategies, focusing on new evidence published since 2006. Use of oral corticosteroids was associated with benefit in an epidemiological study but they are still not recommended; high dose inhaled corticosteroids may cause harm (effect on growth), but they can safely be withdrawn in many patients. Some small beneficial effect of ibuprofen was seen in a multicentre study, but it is unlikely that this will change practice. Altering the imbalance seen in fatty acid metabolism with [omega]3 polyunsaturated fatty acid supplementation may be helpful but therapeutic benefit is not yet proven. Combating cysteinyl leukotrienes has potential but benefit remains to be proved. The beneficial effect of macrolides has been confirmed in patients with milder disease, but caution is needed because of emerging resistance patterns. Renewed research interest in antiproteases has not demonstrated any significant benefit. The ideal therapeutic drug, with the optimal balance of benefit and harm, is not yet available.

http://www.mdlinx.com/PulmonologyLinx/newsl-article.cfm/2000435

Update on the epidemiology and management of Staphylococcus aureus, including methicillin-resistant Staphylococcus aureus, in patients with cystic fibrosis. Stone, Anne a; Saiman, Lisa b. Current Opinion in Pulmonary Medicine. 13(6):515-521, November 2007.

Staphylococcus aureus is one of the first and most common pathogens to be isolated from the respiratory tract of patients with cystic fibrosis. The prevalence of respiratory tract colonization/infection with both methicillin-susceptible and methicillin-resistant S. aureus has increased over the past decade. The clinical significance of colonization/infection with these pathogens is variable, leading to numerous therapeutic strategies: primary prophylaxis, eradication, treatment of cystic fibrosis pulmonary exacerbations, and treatment of methicillin-resistant S. aureus. Studies have demonstrated increased prevalence of S. aureus in clinical laboratories that use selective media. Additionally, small colony variant S. aureus has been associated with persistent infection, co-infection with Pseudomonas aeruginosa, and frequent courses of antibiotics, but this phenotype may be difficult to identify in clinical laboratories. Increased prevalence of methicillin-resistant S. aureus has led to use of oral and inhaled antibiotics in attempts to eradicate this pathogen; these studies have yielded variable results. The epidemiology of S. aureus in cystic fibrosis has changed. Studies are needed to assess the clinical significance of the increased prevalence of both methicillin-susceptible and methicillin-resistant S. aureus, and whether primary prophylaxis or new treatment/eradication protocols are effective.

http://www.mdlinx.com/PulmonologyLinx/newsl-article.cfm/2000434

Continued on page 42

PREGNANCY AND CF

Pregnancy in cystic fibrosis. Tonelli, Mark R; Aitken, Moira L. Current Opinion in Pulmonary Medicine. 13(6):537-540, November 2007.

This review summarizes recent knowledge regarding pregnancy in women with cystic fibrosis, including contraception, pre and postpartum medical care and outcomes, as well as reproductive decision-making. Cystic fibrosis women have a fertility rate approaching that of the non-cystic fibrosis population, and are faced with complex decisions regarding reproduction. Fortunately, recent clinical and epidemiological studies have provided valuable knowledge regarding the medical ramifications of pregnancy in cystic fibrosis women. More is known regarding the short-term medical outcome of the children of cystic fibrosis women. Women with cystic fibrosis who become pregnant should anticipate more medical care and complications during pregnancy than non-cystic fibrosis women, and more care than they normally require for their usual cystic fibrosis maintenance. Underlying cystic fibrosis-related diabetes mellitus will likely become apparent and require intensified treatment, and weight gain may be difficult. Long-term outcome for women with cystic fibrosis does not appear to be negatively impacted by pregnancy. Indeed, cystic fibrosis women who become pregnant and carry a child to term have better survival, even when corrected for lung function and nutritional status, than age-matched cystic fibrosis women who do not become pregnant. The offspring have a higher chance of being born prematurely than in the general population.

http://www.mdlinx.com/PulmonologyLinx/newsl-article.cfm/2000437

ASSESSMENT OF CF

Assessment of Morphological MRI for Pulmonary Changes in Cystic Fibrosis (CF) Patients: Comparison to Thin-Section CT and Chest X-ray. Puderbach, Michael MD; Eichinger, Monika MD; Haeselbarth, Julie MD; Ley, Sebastian MD; Kopp-Schneider, Annette PhD; Tuengerthal, Siegfried MD, PhD [P]; Schmaehl, Astrid MD [P]; Fink, Christian MD; Plathow, Christian MD; Wiebel, Matthias MD; Demirakca, Sueha MD; Muller, Frank-Michael MD, PhD; Kauczor, Hans-Ulrich MD, PhD. Investigative Radiology. 42(10):715-724, October 2007.

As pulmonary complications are life-limiting in patients with cystic fibrosis (CF), repeated chest imaging [chest x-ray, computed tomography (CT)] is needed for follow up. With the continuously rising life expectancy of CF patients, magnetic resonance imaging (MRI) as a radiation-free imaging modality might become more and more attractive. The goal of this study was to prospectively assess the value of MRI for evaluation of morphologic pulmonary CF-changes in comparison to established imaging modalities. Morphologic MRI of the lung in CF patients demonstrates comparable results to MDCT and chest x-ray. Because radiation exposure is an issue in CF patients, MRI might have the ability to be used as an appropriate alternative method for pulmonary imaging. ▲

http://www.investigativeradiology.com/pt/re/invrad/abstract.00004424-200710000-00008.htm;jsessionid=HZ2Tq3Zkm664nrVdV5Qr2CxfKTPpgQrWD7cNTlxLdZmsH95GW212!1071114923!181195629!8091!-1

Laura Tillman, 60, has CF. She is a Director of USACFA and is the Secretary. Her contact information is on page 2.

Calling All Writers

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

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

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

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

However you get it to us, please write.

CF ROUNDTABLE SUBSCRIPTION FORM (Please Print Clearly)

NAME _____ **PHONE ( )** _____

ADDRESS _____

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

E-mail address: _____

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

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

A yearly donation of $10 for individuals, $20 for non-US addresses (US funds only) and $25 for institutions is recommended.
CF Roundtable is available free of charge to those who are unable to donate at this time.

- Annual donation . . . . . $ _____
- Additional donation to defray costs . . . . . $ _____
- Please send me the back issues I have listed on a separate sheet of paper.
  I am enclosing $2.50 per copy requested. . . . . $ _____
- Please send gift subscriptions to the names and addresses I have listed
  on a separate sheet of paper. I have enclosed $10 per subscription ordered. . . . . $ _____

TOTAL . . . . . $ _____

Please do not write in this space

WI 08

Make checks payable to USACFA and mail with this completed form to: USACFA, PO Box 1618, Gresham, OR 97030-0519
Everyone must complete a subscription form annually to be included on our mailing list. Please check mailing label for renewal date.

REMINDERS

- Please notify us immediately of any address changes. Returned mail wastes money and delays mailings.
- To keep our mailing list current, we require the completion of a subscription form every year, even if you are unable to make a donation. Your address label indicates when it is time to renew. Subscriptions stop automatically if not renewed regularly.
- We would like to act as a referral source for active adult support groups. Please send us your group name, leader's name and phone number, number and age range of your members and geographical area covered, and we will add you to our referral list.
- Please let us know of the major occurrences in your life (*e.g.*, *marriages*, *births*, *completion of educational degrees or training*, *career advancement*, *transplants*, *anniversaries*, *birthdays*) and we will print your information in **Milestones**.
- Share your ideas for **Focus Topics**, feature articles or any suggestions for improvements you may have to help make *CF Roundtable* more relevant and interesting to you.
- You can reach **USACFA** and ***CF Roundtable*** at anytime by phone or fax at **(503)669-3561**. (That number always answers by machine.) You may email us at **cfroundtable@usacfa.org**
- Send your questions of a general nature regarding legal issues that relate to CF to our legal advisor: **Beth Sufian, Esq., 811 Rusk Street, Suite 712, Houston, TX 77002-2807**.

HOW TO KEEP YOUR SUBSCRIPTION UP TO DATE

Do you wonder when your *CF Roundtable* subscription is due for renewal? Have you wondered how to tell if it is time to renew? Look at your mailing label. Immediately after your name, there should be a date. That is your renewal date. (On the example, you can see that Kathy is due to renew her subscription in May 2008.) If there is no date or it says (COMP COPY), your subscription is due for renewal.

KATHY RUSSELL 5/08
4646 NE DIVISION STREET
GRESHAM, OR 97030-4628

If it is time for you to renew your subscription, you should have received a reminder with your newsletter. Please be sure to complete and return that form to us. You can help to keep our postage costs down by letting us know your current mailing address. To keep our records up to date, send us a notice when you move. (Any issue of the newsletter that is returned to us costs us about two-and-a-half times the first-class postage rate for that piece. Currently that runs about $3.35 per returned copy.)

Thank you for helping us with this.

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

IMPORTANT RESOURCES

For a directory of pharmaceutical companies that provide free prescription drugs to patients who qualify, write to: Directory Programs, Pharmaceutical Manufacturers Association, 1100 15th St. NW, Washington, DC 20005-1707. Use the information provided in that directory to contact the appropriate companies for information on their specific programs.

United Network For Organ Sharing (UNOS). Phone: **1-800-24-DONOR.** Call for information on transplant centers, access for all patients needing organ transplants and general transplant information.

Transplant Recipients International Organization, Inc. (TRIO): An independent, non-profit, international organization committed to improving the quality of life of transplant recipients and their families and the families of organ and tissue donors. For information write: **TRIO, 1000 16th St., Ste. 602, Washington DC 20036-5705. Or call: 1-800-TRIO-386.**

American Organ Transplant Association (AOTA): Helps defray out-of-pocket travel expenses for transplant recipients. Helps to set up trust funds. For more information write: **American Organ Transplant Assn., 3335 Cartwright Rd., Missouri City, TX 77459-2548.** Or call **(281) 261-2682.** e-mail: **infoAOTA@a-o-t-a.org.**

ADA: To learn how the Americans with Disabilities Act (ADA) applies to you, contact the Disability Rights Education and Defense Fund (DREDF) at **1-800-466-4232** between the hours of 9 a.m. and 3 p.m. Pacific Time. The DREDF has received a federal grant to inform individuals, who may be subject to discrimination, of their rights and remedies. To report a violation of the ADA, call the Equal Employment Opportunity Commission (EEOC) at **1-800-669-3362.**