CF Roundtable
A NEWSLETTER FOR ADULTS WHO HAVE CYSTIC FIBROSIS
AUTUMN 2012

# What to Expect When You're Expecting (Lungs)

*By Piper Beatty*

I get a lot of questions about lung transplant through my blog, A Matter of Life and Breath, but by far the most common is the simple yet personal staple: "What was the hardest part about lung transplant?" And I pretty much always answer this by explaining that, for me (and for most patients I know), the hardest part about lung transplant is managing expectations. As someone who has been living with CF for 30 years (and counting!), I know all too well that the prospect of entering into a new world of deeper breaths, new doctors and new discoveries, and immunosuppression can be just as scary a prospect as it is thrilling. After all, when it comes to trading in your old organs for those of another, even the most hardcore "professional patients" among us will probably have some anxiety to deal with – no matter how much trouble those old CF lungs have given you in the past. The bottom line is that it's hard to know what to expect when it comes to CF and life after lung transplant.

PIPER BEATTY

Look, lung transplant isn't a cure, especially not in the case of cystic fibrosis. It's not a snap-your-fingers-and-go kind of deal. Lots of people I know are in and out of the hospital, even after their surgeries, although the frequency and severity of those hospital stays seems to vary. In any case, transplant isn't a magic bullet. People who think it's going to be one normally end up somewhat disappointed, if not disheartened and disillusioned.

On the other hand, I know very few people with CF post-transplant who actually regret it, and that should tell you something. In my own case, I can tell you that by the time I reached the point of really NEEDING new lungs it was no longer a philosophical question for me. I wasn't pondering the relative pros and cons of life on immunosuppression or the possibilities of rejection. Nope. By the time I needed lungs, all I wanted to do was live. I would have taken odds against all the complications in the world just for one deep breath. I knew transplant wasn't a cure, but I also knew that it had the

*Continued on page 15*

## INSIDE THIS ISSUE

**CF ROUNDTABLE**
**FOUNDED 1990**
**Vol. XXII, No. 4**

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

USACFA needs your tax-deductible donations to fund the printing, production and mailing costs of *CF Roundtable*. A yearly donation of $15 for individuals, $25 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. 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: 248-349-4553
E-mail: cfroundtable@usacfa.org
www.cfroundtable.com



# EDITOR'S NOTES

This issue marks the end of our 22nd year of publishing *CF Roundtable*. We have grown and changed in those years. We started with six directors and officers and now we have 12, including our new Vice President, **Jeanie Hanley**, MD. She replaces **Paul Feld** in that office. We send our congratulations to Jeanie and our thanks to Paul for his service. The rest of the officers remain the same.

We are proud to announce that **Laura Tillman**, our President, was awarded the CFRI *2012 Dave Stuckert Volunteer of the Year* award at the CFRI Educational Conference in California in July. You may read about it on page 17.

On the front page, **Piper Beatty** writes of the expectations of transplants, which is the first of several articles that deal with the Focus topic of: "Organ Transplants – Has It Met My Expectations?". In *Spirit Medicine*, **Isabel Stenzel Byrnes** tells of the spirits of organ donors. **Paul Feld** says that he would, "do it again in a minute". *"So Far, So Good"* is how **Lisa Cissell** writes of her experience. **Andrea Eisenman** tells how her transplant has exceeded her expectations. A change for the better is how **Rachael Mauger** describes her transplant. In *A Deep Breath In*, **Debbie Ajini** lets us know that she received new lungs - in September! **Colleen Adamson** uses *Transplant Talk* to let us know of her trials with hair loss post-transplant. On page 22, the offering from *The Breathing Room* offers another look at transplant. In *Speeding Past 50*, **Kathy Russell**, also discusses transplants.

*Ask the Attorney* finds **Beth Sufian** answering questions about employment, insurance and FMLA leave. Laura Tillman compiles so much good information in *Information from the Internet*. *Coughing With A Smile* finds **Jennifer Hale** talking of change and waiting, and she has a piece in the *Poetry Corner*. *In The Spotlight* features **Paul Albert**, who is coming up to 20 years post-transplant. In *Poetry Corner*, **Simon Greenburg** writes of his feelings about his father's lung transplant.

Laura Tillman and **Maria Fioccola** each write of their experiences at the 2012 CFRI Educational Conference. **Paul Feld** writes of the 2012 CFRI RetrEAT.

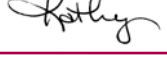
On page 19, we ask for your help with funding USACFA and *CF Roundtable*. With your help we can continue to provide a forum for adults who have CF. Also, remember that a subscription to *CF Roundtable* makes a great gift for anyone who has an interest in CF, and now you can even subscribe online at: cfroundtable.com.

On page 5, please take the time to read of the awards that USACFA gives out. Are you aware of someone who should receive one of these? Get your nominations in to Beth Sufian, soon, because the deadline is December 15, 2012.

Please take the time to check out the future Focus topics that are listed on page 3. Perhaps one of these will motivate you to write an article. If you are concerned about your writing skills, let us assist you with your writing. We are happy to help.

I hope your winter is mild and that you keep warm and comfy.

Stay healthy and happy,



**Publication of CF Roundtable is made possible by donations from our readers and grants from Sustaining Partners - CF Services, Abbott and Boomer Esiason Foundation.**

# Benefactors

## BRONZE

**Colleen Adamson**
**Blanche & Derwin Ball**
(in memory of Marsha Ball-Waldo)
**Diana Compton**
**Martha Franz, MD**
**Michael Gallagher**
**Elizabeth W. Hissing**
**Janet King**
**Louise Jordon**
**Edward Kinney**
**Theodore Kowalski**
(in memory of Joe Kowalski)
**Kim Nunnari**
**Jim & Carol O'Brien**
(in memory of their son Ken O'Brien who would have been 50 on November 24, 2012)
**Donna Olsen**
**Roger Postlethwaite**
**Judith Riley**
**Ann Robinson**
**Jennifer Staashelm**
**Deb Stallings**
**Hatsuko Arima Stenzel**
**Robert Tate**
**Sharon Thompson**
**Laura Tillman**
**Marjorie Winokur**

## SILVER

**Gayle Greenberg**
(in honor of Mitchell & Rebecca Greenberg's wedding anniversary and Mitchell Greenberg's lung transplant second anniversary)
**Amy Novelli**

## GOLD

**PMD Healthcare**

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 - $4,999 Platinum Benefactor. Donations over $15 are tax deductible. Please make checks payable to USACFA, Inc. Send donations to:
**USACFA, Inc., P.O. Box 151024, Alexandria, VA 22315-1024**

# LOOKING AHEAD

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

**Autumn (current) 2012: Organ Transplant - Has It Met My Expectations?**

**Winter (February) 2013: Osteoporosis, Osteopenia And Other Skeletal Issues.** (Submissions due December 15, 2012.) Tell us of your experiences with your bones. Do you have osteopenia or osteoporosis or any other skeletal problems? How are they being treated? What tips do you have for our readers?

**Spring (May) 2013: Gastro-Intestinal Issues.** (Submissions due March 15, 2013.) Does your G-I system give you problems? Do you use enzymes? Is one better than another for you? Have you had recurring problems with your G-I system? Tell us your experiences.

**Summer (August) 2013: Motivation – What or Who Keeps Me Going.** (Submissions due June 15, 2013.)

# ASK THE ATTORNEY

## Questions From the Readers, Answers From the Attorney

*By Beth Sufian, JD*

*The past three months have brought many questions about co-pay assistance, determining when to stop work and what to do if you lose insurance coverage. 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 families and their CF Care Center teams. The Hotline is proudly sponsored through a grant from the CF Foundation. The Hotline can also be reached by e-mail at: CFlegal@cff.org.*

### Question 1: When Should I Stop Work?

Many adults with CF work in a variety of jobs. Some people with CF can work for many years while others find that at some point working has a negative effect on their health and they must stop work to spend more time taking care of their health.

There is no magic pulmonary function number that indicates a person should stop work. People should determine if their work schedule prevents them from performing necessary medical treatments, exercising and getting enough rest. If there is no way to take care of oneself while working full time, alternatives to full time work should be explored. Most employers do not offer health insurance to part time employees, so before switching to be a part time employee make sure that the employer offers health insurance to part time employees. If people wait too long to stop work they may find it difficult to improve their health once they stop work. People should make sure they stop work at a time when they will still be able to improve their health with increased time spent taking care of themselves.

### Question 2: I cannot afford my co-pays for medications. Is there any organization that can help?

The CF Patient Assistance Foundation (CFPAF) provides co-pay assistance for certain medications. The CFPAF can be reached at 1-888-315-4154. The CFPAF is a subsidiary of the CF Foundation. However, the CFPAF does not provide assistance for all medications taken by a person with CF. A person who needs copay assistance for medications that are not covered by the CFPAF will have to contact each drug company separately and complete paperwork for copay assistance for that drug. Typically, a person will need to submit copies of the IRS 1040 that has been filed with the IRS for the prior year. Sometimes, if an adult is classified as a dependent on a parent's IRS 1040 form, then the parent's income will be considered if the adult applies for copay assistance. Different companies use different income criteria to determine if a person is eligible for copay assistance.

BETH SUFIAN

### Question 3: Can I take FMLA leave and then take vacation time and sick leave?

An employer can run FMLA leave concurrent with vacation time, sick leave and short term disability or long term disability benefits. For example: if Jane is sick and needs to be hospitalized for three weeks, she can request FMLA leave if she has worked for her employer for one year prior to requesting the leave, and she has worked 1250 hours in the past year, and her employer has 50 or more employees in all offices within a 75 mile radius. However, Jane's employer can require her to use her two week vacation time and one week sick time before her FMLA time. Therefore, if Jane is out sick for three weeks she would only have nine weeks FMLA time left to use in the future. The 12-week FMLA leave is reduced by any other leave the employer gives the employee. FMLA is a total of 12 weeks and is unpaid.

### Question 4: I just received notice that I have been working too much and so I have lost my SSDI benefits and lost my Medicare coverage. Can I get the Medicare back because I have such high drug costs?

Many people mistakenly think that Social Security will consider

whether they have to take expensive drugs to treat their disease when determining if a person is eligible for benefits. However, Social Security does NOT consider a person's drug costs or if the person needs health insurance coverage when determining if a person is eligible for benefits or if benefits should be terminated. If a person does not meet medical and non-medical eligibility criteria, then SSA cash benefits stop and so do the insurance benefits that come along with SSA benefits. For example, if a person loses Social Security Disability benefits he also loses Medicare benefits. The only exemption would be if a person is enrolled in the "Ticket to Work" program. Then if the person returns to work the SSD check stops, but the Medicare benefits continue for a certain period of time. If a person loses SSI benefits then the person also loses Medicaid benefits. Make sure you understand SSA medical and non-medical criteria so that you can keep receiving SSA benefits and Medicare or Medicaid benefits. In many states there are very few options for insurance coverage. A person with CF may be able to piece together free drug programs to obtain some of their drugs but, without any insurance coverage, a person will not be able to pay for home health services, hospitalization, doctor visits, PFT tests, sputum culture tests and many more medical services. It is important to make sure you understand the consequences of your actions before taking action that results in a loss of SSA benefits and a loss of insurance coverage. ▲

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

# Nominations for USACFA Awards...

Here is your opportunity to make nominations for the two awards given by USACFA. We feel that you may know of someone who deserves one of these awards. Please read the requirements carefully.

Read about each award below and then e-mail an explanation of what your nominee did and how that exemplifies the spirit of the award. Please send nominations, by December 15, 2012, to Beth Sufian at: bsufian@usacfa.org.

**The Jacoby Angel Award** was established in memory of Dr. Jack Jacoby who served as a CF physician at the St. Vincent's CF Center in New York. He was Medical Advisor to USACFA and wrote a medical column for *CF Roundtable*. The Jacoby Angel Award recognizes an adult who has CF and has made a significant contribution to the life of one or many people. The person or persons who benefitted from the contribution may or may not have CF.

In the past, the award has been given to Robyn Petras, who helped a fellow person with CF in need; Susan Burroughs, who founded and directs an organization that offers financial assistance to people with CF; Michelle Compton, who started the Breathing Room and fostered artistic expression within the CF community; Pammie Post, who was a long serving Director of USACFA before she received the award and who gave much of her time and energy to a variety of CF causes.

To nominate someone for the Jacoby Angel Award, please e-mail us (by 12/15/12) a short (no more than one page) explanation of what your nominee did and how that exemplifies the spirit of the award. To qualify for this award, the nominee must be an adult who has CF and must not be a member of the board of directors of USACFA.

**The USACFA Founder's Award** recognizes a person who has done something outstanding for adults who have CF. The ideal nominee will be someone who has noticed a need within the community of adults who have CF and has done something to address that need. The person may or may not have CF.

Previous recipients were Lisa McDonough, who started *Roundtable* which came before *CF Roundtable;* Dr. Jim Yankaskas, who pioneered specialized care for adults with CF; Darlene Hello, who led a grass roots effort to save an adult insurance program in Texas and Bev Donelson, who founded a pharmacy to serve the needs of people with CF.

To nominate someone, please e-mail us (by 12/15/12) a short (no more than one page) explanation of how this person did something outstanding for the community of adults who have CF. This award may go to anyone who is not a member of the board of directors of USACFA.

*Send all nominations to Beth Sufian at: bsufian@usacfa.org, by December 15, 2012.*

# SPIRIT MEDICINE

## The Spirit of our Organ Donors

*By Isabel Stenzel Byrnes*

Last Saturday, I joined the annual Donate Life Walk in Northern California. Hundreds of people came out with buttons, hats and t-shirts boasting photos of smiling faces - faces of people whose physical lives are in the past. To quote Catherine Martinet, former "Spirit Medicine" author, these peoples' "absence was everywhere present." Yet through organ donation, storytelling, and jubilant recipients like myself, some part of these donors remain alive.

This brings me to a vivid memory. In 2005, just one year after my lung transplant, I attended my first concert with new lungs. I vividly remember rocking it out and screaming at the top of my lungs in the amphitheatre. I felt so fully alive in the vast crowds. Then, I had an existential moment: I wouldn't be here without my lung donor. Suddenly, without warning, I was overcome with a sudden rage: I sensed that my donor was angry for not having the chance that I was having here at this concert. It was so in contrast to when I woke up after surgery, when I felt an intense peace and love for my donor and my lungs. That moment inspired an essay I wrote from my donor's perspective, called "Gypped." (see editor's note at end)

I don't know if this was just my unconscious speaking, my imagination, a spiritual visitation, or just my brain synapses creating this thought; but I do know that I'm not the only organ recipient to have felt something like this.

Having a transplant lends itself to highly complex psychological reactions. Themes such as worth, guilt, unfairness are blended with blessing, grace, purpose. And spiritually, there are so many unanswered questions. Why did we get this gift? Where is my donor's spirit, and what is he thinking or feeling?

I have talked with several of my CF friends who have received lung transplants about the existence of our donor's spirit inside of us. Does this spirit have the potential to support us through life or, God forbid, make bad things happen to us? If we wonder about these things, what can we do with this?

I recently read about *Mumyo no I*, or "The Well of Ignorance," a highly praised 1991 play written by Tokyo University immunologist, Dr. Tomio Tada. Performed in the traditional dance theater style called *Noh*, (which is similar to Kabuki) the play is about a fisherman who is knocked unconscious in a storm and taken for dead. The wealthy father of a severely ill young woman summons a doctor, who removes the fisherman`s heart and uses it to save the woman. Tada chronicles the odyssey of the unfortunate heart donor, not alive enough to join the living, yet not dead enough to join the deceased. The play highlights the ambiguity of the fisherman's death and the young woman's tormented guilt. The fisherman's spirit asks, "Am I living, or am I dead?" He lives in this netherworld, unable to cross over to a peaceful afterlife. The theme of the play is that the unsettled spirit of the donor haunts the heart recipient, and eventually curses all those who were part of the operation. The young woman tries in vain to purify herself but finally succumbs to the curse.

ISABEL STENZEL BYRNES

When I first read about this play, I felt repulsed and angry. How dare Japan's popular culture continue to perpetuate ignorance, when Japanese people are already plagued with misunderstandings about brain death! When I calmed down, I forced myself to look at this story from its cultural context. Japan, like most of Asian cultures, has had thousands of years of religion based on superstitions. Since Japan's religion has no single diety, superstitions might serve as a moral compass for the people. Even today, beliefs in the afterlife are influenced by the death event and the status of the corpse. With no religious values for generosity or unconditional giving, no wonder the fisherman, the organ donor in this play, is portrayed with conflict. And, like any country with a history of primitive hygeine, for centuries, most Japanese

people died of infectious diseases. Therefore, Japan adopted the view that anything to do with death was dirty and contaminated. And it makes sense that organ recipients would be viewed negatively as well.

I realized that any culture can adopt any impression of an organ donor's spirit. I am grateful to be from America, where organ donors are praised and honored for their sacred gifts of life. Japan's views could be ours, and ours could be theirs. Our societal views towards the goodness of organ donors sure helps me to incorporate a belief that my donor is good, and his spirit is blessing me. In my own psychology, I deliberately think good thoughts about my donor. I would like to believe he is pleased with me, and that he does watch over me. I'll never know the truth, but I can choose to think this way.

Clearly, each and every organ recipient will find his or her own way to make sense of the spirit of his or her donor. Some may talk or pray to their donor; some may appreciate a presence inside of them; some may feel saddened at the mere thought of their donor. Some may feel nothing at all—the gift of lungs was a biological match, and that was it.

Like many of my transplanted CF friends, I try to embrace this positive gift by honoring my donor's spirit. I've heard many recipients say "I live for my donor." Perhaps underneath the urge to honor one's donor is an unconscious desire to appease some guilt, and to reconcile the tragedy of someone's death with the miracle of our life. To feel the need to live for another person may be too much pressure to put on ourselves.

The best way I can honor my donor is simply to tell his story. *Xavier Cervantes was an 18 year old high school student who loved trucks, helping people, and being active. He had identical twin sisters, a beautiful girlfriend and great friends…* Of course, not everyone is so lucky to know a few details about their donor. I learned them after writing to his family several times, and receiving a response when they were ready. Since Xavier is not here to tell his story, I can help do it for him. Through his story, and our intertwined stories, he is remembered.

Another way to feel the positive spirit of my donor is by making my donor proud. My friend Dottie Lessard inspires me with her personal motto: "Live like donor is watching." Certainly, doing things that make our donors proud will make us proud. To try to accomplish great feats - climbing a mountain, running a marathon, winning medals at the Transplant Games - are ways to honor our donors. For some, just returning to our normal lives is also a real and simple way to honor one's donor. And it's not always easy to honor our donors, especially when transplant complications overwhelm us or life gets hard. Some day I may face rejection, and have to engage in a hardcore dialogue with my donor. For now, though, what helps me make peace with my donor is to take the time each day to remember my donor, to thank him for another day, and to keep on living to tell his story. ▲

---

*Isabel Stenzel Byrnes is 40 and has CF. She lives in Redwood City, CA. She wrote this essay on September 10th, 2012, which would have been Xavier's 26th birthday.*

Editor's note: If you wish to read "Gypped", which is in adult language, please send your request to: cfroundtable@usacfa.org and be sure to ask for a copy of "Gypped".

---

# CF Living

CF Living

Check out the new *CF Living!* As many of you may know, *CF Living* is an educational program that offers information and support for those living with or caring for someone with cystic fibrosis. Genentech is proud to offer you this updated form of support, and we encourage you to check out all the new features on the site that are now available. The new *CF Living* is designed to help you work more closely with your Care Team, learn about treatment options, and provide interactive educational resources so you stay informed. Enroll today at: https://www.cfliving.com/ to begin taking part in this informative program!

# SPEEDING PAST 50...

# Doing What You Can, When You Can

*By Kathy Russell*

Wow, it's autumn again! It seems to come earlier and earlier, but of course it always comes at the same time in a year. It is only a sign of my increasing age that makes it seem to come faster. I can remember when I was little that summer always seemed to go by so fast. Then, when I was working, it seemed that the lovely summer weather went by so quickly. Of course that was only because I saw so little of the nice weather on my days off. Then after I retired, summer seemed to "mosey along" and last a lovely, long time. Now, I am back to feeling that summer goes by too quickly. I really shouldn't complain, because we had a marvelous summer where I live. I just don't want it to end.

Autumn has its own beauty. The apples on the trees out back are ripening and are so sweet. The fruit on the Italian plum trees are deep purple and wonderfully sweet, too. The Danish squash and sweet corn from the farm stand are really tasty. Friends have shared big, ripe tomatoes with us and we have enjoyed some wonderful BLTs. Yum! Yum!

For the first time in a few years I was able to do some canning. I know that many people think of canning as old fashioned, but I love being able to do it. My husband, Paul, helped me and we made bread and butter pickles and sweet pickle relish. I know that both of these products can be purchased at stores, but I haven't found any that are good enough for us. I don't want anything that is made with high fructose corn syrup or artificial sweeteners. Most of the commercially available products have one or the other. Also, when we make them, we can control the ingredients and the way the pickles are cut. (I know, that seems picky, but that's what I like.)

When I look at my pantry and see jars that we have produced, I feel very wealthy. It gives me a sense of security to have homemade foods. Paul makes our bread and it is great. We try to use ingredients that are grown without pesticides or antibiotics. We wash all produce before using it. We go to these extra efforts to try to eat only the safest foods that we can. There are many things over which we have little control, but we can have some over what we eat.

Having some control in life can feel out of reach for many of us. We have little control over how many meds we take and how many treatments we do. Or should I say that, if we want to keep our docs happy, we have little control. That can cause some frustrations as we need more health interventions. Every day we can feel a little less in control.

One way to ease that sense of frustration is to help others. Many of us participate in online support groups. That is a way of helping ourselves as well as others. Some people may speak at fund-raisers or educational groups. Some may write for publication. All of these are ways to share and help. Now I'll talk about another way to help.

KATHY RUSSELL

When I saw that the Focus topic of this issue was "Transplants", I thought that I would have nothing to say about that. On reflection, however, I realized that there is a lot more to transplants than just being the recipient or donor. There are so many ways that we can be involved, without receiving any organs ourselves.

A friend of mine who has CF had a heart-lung transplant (HLT) at Stanford Medical Center in Palo Alto, California in 1991. He lived in Portland, Oregon and had to find living accommodations in Palo Alto for after his release from the hospital. At that time, there was an apartment available through the hospital for only the first six weeks post-hospital release. He still had to have a place to stay, until he was allowed to return home to Oregon.

Housing became available to him and his mother, who was his caregiver for the post-op time, at the home of a local family. This family had a young relative who had CF, so they were eager to help. They were so warm and welcoming to our friends and made it possible for them to stay as long as the docs wanted him there.

We were very moved by the kindness of these people who did not know our friend, but who wanted to help. We wished that we could have helped in a similar way. The following year, we got our chance.

We read in our local newspaper of

a man who was waiting for a new heart. He lived in Eastern Oregon and needed to move to the Portland area to await his transplant. It is expensive to move to the Portland area and to have to keep up a home somewhere else. They were looking for some help.

We were unable to give them money to help with their costs, but we might be able to help with housing. We contacted them, through the newspaper, and offered the small but workable apartment that is over our garage. It is only a studio, but it is private and has a kitchen and a bathroom. They would still be responsible for their phone and electricity, but everything else was covered since we wanted no rent.

After they looked at the apartment, they decided that it would work for them. They moved in during the latter part of January, 1992. They continued to try to collect enough funds to cover the cost of his surgery. The waiting was very difficult for them and he had a few strokes, while he was waiting.

In late January 1993, he finally got the call that there was a new heart for him. Paul and I were delighted to be able to drive him and his wife to the medical center. When we said "Good bye" to him, we said that the next time we saw him he would be feeling much better…and he was. We visited him at about five days post-op and could hardly believe how pink and well he looked.

He had an uneventful recovery and was able to return to our place after about two weeks. While he recuperated, he got back into the way of life that had been impossible for him for so long. Seeing him playing catch with Paul was one of the highlights of our lives, because it was something that he never had been able to do. They stayed with us until June and then, when the docs said it was okay, they returned to their home in Eastern Oregon. We still hear from them regularly and he continues to live and thrive. (The friend who had the HLT is alive and well, too.)

I know that there are some of you who have wondered how you could help someone who was waiting for transplant or had already had a transplant. Offering housing, either pre- or post-transplant, may be one way. If you have an extra room and live near a transplant center, consider offering your assistance. It may make transplant possible for someone who might not be able to manage it otherwise. It really feels good to be able to help.

Transplants are a really big deal and take a lot of thought, energy and money. You may not be able to donate money for transplant costs, but you might be able to offer housing or transportation or something else. Try to think of what you would need if you were in that person's shoes and see if you can assist in any way. Every little bit helps.

If nothing else, each of us can offer our support and concern for those who are contemplating such a momentous undertaking. So it seems that we each must do what we can when we can.

Please stay healthy and happy. ▲

*Kathy is 68 and has CF. She is the Managing Editor of CF Roundtable. You may contact her at: krussell@usacfa.org.*

# Information from the Internet...

*Compiled by Laura Tillman*

## PRESS RELEASES

**The Household Item That Could Have Cystic Fibrosis Patients Breathing Easy**

A group of researchers published a paper highlighting how infection in CF patients may be prevented and possibly treated with a multifunctional chemical known as sodium bicarbonate (baking soda). They found that the CFTR gene mutation changed one of the lung's defense mechanisms, known as the airway surface liquid (ASL), by lowering the pH (i.e. more acidic) and rendering it less able to kill the bacteria known to cause problems in CF: Staphylococcus aureus and Pseudomonas aeruginosa. The team decided to try increasing the pH of the ASL by aerosolizing bicarbonate, which is a gentle alkaline known to raise pH. The result was quite promising. In cases where bacterial infection had not yet begun, lungs remained healthy. If bacteria were already present, the bicarbonate-treated ASL was able to fight off infection.
http://tinyurl.com/bl7q3do

**New proteins to clear the airways in cystic fibrosis and COPD**

Researchers show that the "SPLUNC1" protein and its derivative peptides may be able to help thin thick mucus by affecting the epithelial sodium channel (ENaC). To realize what part of SPLUNC1 is basically inhibiting sodium channel, researchers have gradually fragmented this protein. After

*Continued on page 10*

# 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

**Danelle DeCiantis**
Manchester, CT
46 on June 23, 2012

**James Lawlor**
Hunstville, AL
26 on June 10, 2012

**Susan LeBoeuf**
Laurel, MD
60 on August 11, 2012

**Kathy Yoder**
Portland, OR
50 on August 16, 2012

### Wedding

**Colleen & Scott Adamson**
Alexandria, VA
15 years on June 28, 2012

**Danelle & Crescent DeCiantis**
Manchester, CT
19 years on October 23, 2012

**Andrea Eisenman & Steve Downey**
New York City, NY
4 years on September 13, 2012

**Mitchell & Rebecca Greenberg**
North Potomac, MD
12 years on August 5, 2012

### Transplant

**Colleen Adamson,** 43
Alexandria, VA
Bilateral lungs
14 years on July 3, 2012

**Piper Beatty,** 30
New York, NY
Bilateral lungs
2 years on June 12, 2012

**Danelle DeCiantis,** 46
Manchester, CT
Bilateral lungs
13 years on June 4, 2012

**Geoff Earnest,** 36
Portland, OR
Bilateral lungs
6 years on June 5, 2012

**Mitchell Greenberg,** 39
North Potomac, MD
Bilateral lungs
2 years on July 20, 2012

## ACCOMPLISHMENTS

**Andrea Eisenman,** 47
New York City, NY
Won a Gold medal in singles tennis
And a Gold medal in doubles tennis
At the Transplant Games of America 2012
Grand Rapids, MI
July 28-Aug 1, 2012

**Laura Tillman,** 64
Northville, MI
Received The 2012 Dave Stuckert Memorial Volunteer Award
Presented at the CFRI Conference
July 28, 2012

**Kathy Yoder,** 50
Portland, OR
Is now breast-cancer-free

## NEW BEGINNINGS

**James Lawlor,** 25
Hunstville, AL
Started first fulltime job
On June 4, 2012

**James Lawlor,** 26
Hunstville, AL
Purchased first home
On August 17, 2012

### Transplant

**Debbie Ajini,** 43
Shelby Township, MI
Bilateral lungs
July 28, 2012

**TILLMAN** *continued from page 9*

fragmenting 85% of protein, they have realized that the inhibitory function lies in the other 15% and created a synthetic peptide similar to the region. Subsequently, they tested to see whether this peptide inhibits the sodium channel. The results were positive: SPLUNC1 synthetic peptide blocked ion channel function and fluid absorption.
http://tinyurl.com/8aqptof

**Grifols Initiates Safety Study of Inhaled Alpha1-Proteinase Inhibitor (Human) Following Orphan Drug Designation for Cystic Fibrosis**

Grifols, a global healthcare company based in Barcelona, Spain, announced plans to initiate a safety

# Mailbox

I am an adult with CF and a double lung recipient as of July 2006. I currently live in Aptos, California, and am very active in Mountain biking. I work at home as a consultant in Mechanical Engineer.

Tom Martin
Aptos, CA

I am a 60-year-old adult with CF. I am married to David (27 years in October) and we have two cats, Lily and Tigger. We currently reside in Laurel, MD but are in the process of having a new home built in a 55+ community in Marriottsville, MD. I do volunteer work with a non-profit group that supports adults with developmental disabilities. I help the adults with arts & crafts projects and I also teach a social skills class. I'm also involved in a Catholic Ladies of Charity organization that reaches out to the poor of our community and I participate in Pro-Life activities.

Susan LeBoeuf
Laurel, MD

I am a 30-year-old female with CF living in NYC with my adorable puppy. I received a transplant on June 12, 2010, at New York Presbyterian/Columbia hospital.

Piper Beatty
New York, NY

Thank you all for all you are doing for others with CF and their families.

Gayle Greenberg
Potomac, MD

Once again it is time to renew our subscription. This CF family appreciates all your efforts for providing us with current information and hope.

Judith Riley
Brooklyn, CT

Melissa (Cokelet) Brown was awaiting her second double lung transplant. She was in Columbia Presbyterian Hospital in New York City for 10 months. She left behind her seven year old twin daughters, Taylor and Madison. She fought a most courageous battle which we admired her for. She is terribly missed by many!

Maureen Cokelet
Hazlet, NJ

Thanks for sending a renewal notice. I was always worried about missing the notation on the envelope.

Janet King
Tenafly, NJ

Thank you and your team for a great newsletter which supports and gives valuable information to our adult CF community and for those of us who are involved in their successes and challenges.

Marie Roulier
Storrs Mansfield, CT

[I am the] husband of Leslie Alford, who died June 12, 2012, at 51 years of age during transplant surgery, due to complications from a 1991 experimental procedure. Thank you, Methodist, for giving my best friend and bride her best chance for survival. Thank you Father for removing ALL her pain and tears! She graduated Magna Cum Laude from Texas A&M ('83) with a psychology degree, then with honors from U of H Clear Lake in psychology. She gave birth naturally, with no meds, to an incredible son. She worked for 17 years as a Social Worker at San Jac Hospital. She maintained a busy schedule at church teaching Bible study, ringing hand bells, singing in the choir, volunteering with registering folks and helping at many events. She traveled the US to the Redwood Forests, the east coast, a white water rafting trip, a hot air balloon ride, and still had enough to be married to a Marine/police officer for 27 years. Go for it!

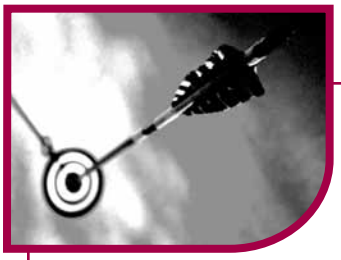
David Alford
Baytown, TX

trial of a novel, inhaled formulation of alpha1-proteinase inhibitor [Human] later this year. In April, the U.S. Food and Drug Administration (FDA) granted orphan drug designation for Grifols' inhaled alpha1 formulation as a treatment for cystic fibrosis.

PROLASTIN-C is made from human plasma. Products made from human plasma may carry a risk of transmitting infectious agents, e.g., viruses and, theoretically, the Creutzfeldt-Jakob disease (CJD) agent. http://tinyurl.com/cjhth47

**Bacteria infecting the lungs of individuals with Cystic Fibrosis (CF) can**

*Continued on page 13*



# FOCUS TOPIC

## ORGAN TRANSPLANT – HAS IT MET MY EXPECTATIONS?

# ...In A Minute...

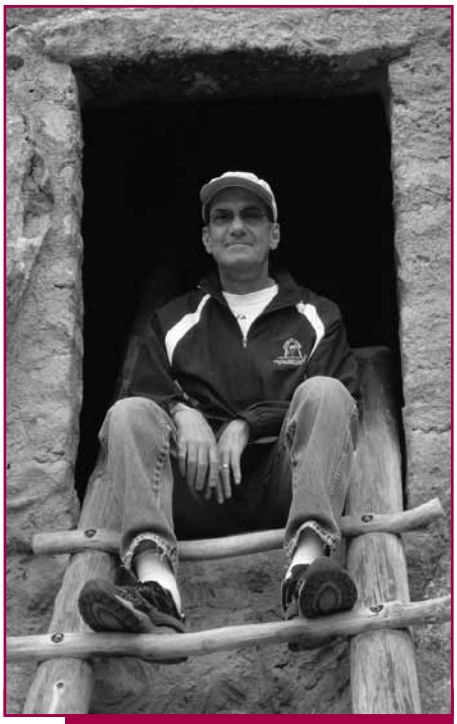
*By Paul Feld*

My personal transplant experience began in 1996 when, at the tender age of 39, my $FEV_1$ crossed that magic line of "less than 30%", where most transplant centers begin to have you get listed. I was no different, but the 'rules' were. I was on a list at Barnes-Jewish Hospital, associated with the Washington University School of Medicine, and was put on the bottom of the first-in, first-out transplant list. It was a long list, full of periods of time when I was 'inactive' and doing too well to be listed, so they stopped counting my days. Even though I ended up waiting a little over 1000 days, those days accumulated over eight years, and I was transplanted in October, 2004, at the age of 47.

It's now almost eight years later, and I have much experience to look back on. I would do it again in a minute, as these last eight years have meant so much to me. But, they have been very far from care-free, and I hope to provide some insight into 'life after transplant'.

It's important to understand post-transplant statistics as far as life expectancy goes. Typically, for every year you survive post transplant, your life expectancy drops 10%. After one year, 90% of post-transplant recipients are still alive, after two years, 80%, etc, so that after 10 years, only about 10% of transplant patients are still living. While those may be considered grim statistics, you must realize that without transplant, life expectancy for most recipients would be less than two years. Personally, I have been very blessed to have lived almost eight years post transplant, and have accomplished all sorts of things I could not have done without it. Which for me makes the problems worthwhile, but it certainly has not been an easy road, and no one promised me it would.

In my first year post-transplant, I experienced both acute and chronic rejection. This is not too unusual for most transplant patients. The trick is finding the right combination of rejection medications that work for you, and being fortunate enough to get through year one, the toughest part of time. You first have to recover from your surgery. This will always vary by patient, but you can expect a tough 3-9 months. Usually after that you are on top of the world for a while, as you find you can do things you haven't been able to do in years.



PAUL FELD IN NEW MEXICO.

For me, the highlight was participating in the 2006 US Transplant Games, and, meeting my donor family during those games. Over the course of years one and two post-transplant, I was challenged to find the right rejection meds. Cyclosporin, Cellcept, Myfortec, and a couple other common meds came and went, all causing me some serious side affects or kidney toxicity. When my creatinine level hit 2.3, my docs switched me to only prednisone and rapamune, and they are currently my 'last resort' rejection meds. When and if they fail, so will I. They have been OK for almost four years now.

I could write a short book of my problem list since transplant. It has been better for some recipients, worse for others, and there are certainly no consistent problems from one recipient to the next. I have had three lung collapses, chest tubes re-inserted several times to drain liquids, countless infections and IV therapy, and several facial surgeries from skin cancers. This is not an end-all list, but simply the highlights.

I can easily deal with the infections, as I became an expert at this pre-transplant. I'll never get used to chest tubes, and I doubt anyone could. Lung collapses almost always correct themselves, given enough patience and time. For me, the long-term problems with these were the need for a stent on one of my left bronchial tubes, and a failed right middle lobe of my 'new' right lung. The problem with these spots is they are a wonderful home for infections to begin and proliferate.

The problems that bug me the most, however, are these consistent cancerous growths on my face (ear, nose, and temple), that require MOHS surgery. They are probably caused by my remaining rejection medications,

as my rapamune prescription always comes with a couple pages of skin cancer warnings. I understand through the transplant community that this is a very common problem. Unfortunately, there are no common solutions. In my case, I continue to have these minor surgeries to survive.

The latest year (year eight for me) has been a year of frustration and reflection. I get really down having to continue to go on IVs for infections every couple months. The skin cancers drive me bananas, and normal healthcare visits continue to increase the longer out from transplant that I go. My life, at 55, is still a considerable blessing, but the 'getting old' part is mixed with blessings and normal 'getting old' things. It's just a lot harder with transplant and CF, and you can never just rest on your laurels.

Again, I'd do it again in a minute. I would do it for both me and my family. I can't finish this article without mentioning my family. Just like during transplant, one cannot make it without family support and my wife, Kristi, was there all the way with me. She still is, and my struggles are her struggles. She realizes that, statistically, she will be without a husband sooner than she wants and I think she has mental challenges with that. She wants to prepare for it, but not too fast. I retired recently and she carries both the financial and insurance burden for our family. This puts an unfamiliar pressure on her and limits certain things in her life on which I am sure she wishes did not have limits. She does all this for us, mostly with a smile, but at times with challenge. Be sure you have someone willing to make this sacrifice, as I am sure I could not have been successful without that support. Thank you, Kristi! ▲

*Paul is 55 and has CF. He is a Director of USACFA. His contact information is on page 2.*

**TILLMAN** *continued from page 11*

**show considerable genetic diversity, even among bacterial isolates obtained from a single patient according to new research funded by the BBSRC published this month in the Journal of Bacteriology.**

Scientists found that the genome sequences of Pseudomonas aeruginosa could be different, even among cohabiting isolates obtained from a single person. This inherent genetic diversity may be a factor that makes treatment more difficult. Previous genomic analyses seemed to indicate that the bacterial populations in these patients were rather uniform and did not display much genetic variation. However, this was contrary to what the clinicians treating the patients experienced. They found that, even among the bacterial colonies isolated from a single patient, a range of antibiotic resistance profiles was often evident. This is a strong indication that these isolates are likely to be genetically different. The researchers used state-of-the-art DNA sequencing to decipher the genome sequences of randomly chosen pairs of bacterial isolates, with each pair being taken from a different CF patient. Pairs of isolates from three patients were studied in all. The study revealed that the genome sequences of the isolates comprising each pair differed from one another, sometimes substantially.
http://tinyurl.com/cglrlrl

**OrPro Therapeutics Receives NIH Grant Award to Advance Development of Recombinant Thioredoxin for Treatment of Cystic Fibrosis**

The grant enables OrPro to advance development of its lead product, ORP-100, for the treatment of cystic fibrosis. ORP-100 is a recombinant engineered variant of thioredoxin, a human lung protein that has demonstrated in laboratory studies a potent ability to increase the fluidity of mucus. ORP-100 will be administered through an advanced aerosol delivery system, and in contrast to DNA-degrading mucolytics, targets the adhesive protein gel network that is common to all patients with obstructive mucus.
http://tinyurl.com/8ppoxf8

**Research Investigates Synedgen's Promising New Treatment to Help Clear Airways of Cystic Fibrosis Patients**

Synedgen, Inc. has preliminary data showing its lead molecule, a proprietary biocompatible polysaccharide derivative, PAAG, can reduce viscosity of CF sputum. These compelling results have led to a new research agreement with leading cystic fibrosis researchers at two different CF Centers in the US to investigate PAAG as a new therapeutic to enhance airway clearance in CF patients. Sputum samples will be collected and studied from CF patients with good to poor lung function to understand the role of PAAG on these varying levels of disease severity and level of infection.
http://tinyurl.com/bqyo766

**Gene network restores CF protein function**

Researchers have discovered a genetic process that can restore function to a defective protein, which is

*Continued on page 23*

# Lung Transplant? So Far, So Good!

*By Lisa Cissell*

My life before and after transplant is like night and day. Before my transplant, my life had slowly morphed into a hermit-like existence. My lung function had slid down to 23%, I was on oxygen 24/7, and just basically felt awful. Previously very social and independent, I was rarely leaving home and had to rely on friends and family to do everyday tasks for me such as grocery shopping, laundry and house cleaning. I remember how difficult it was to do even simple things such as walk to the mailbox, take a bath/shower, or simply walking room to room. The thought of having a lung transplant was very scary, but the thought of continuing to live this way was an even more frightening prospect.

One of the hardest parts of the process was deciding to move to a different state to have my transplant. There were two deciding factors. One was that my insurance company would cover significantly more if I had my surgery in one of several chosen lung transplant centers. The closest centers to my home in Kentucky were St. Louis, Indianapolis, and Durham, NC. The second deciding factor came into play when two dear friends, Paul and Kristi, who live in St. Louis, graciously offered to let me and my beloved dog stay with them while I waited for my transplant and to serve as my caregivers when my family couldn't be with me.

So, with the decision of where made, I took a couple of months to take care of my business at home and then relocated to St. Louis. Unbelievably, I received the call that there were lungs for me only EIGHT DAYS after moving! My little dog and I didn't even have

LISA CISSELL

time to get settled! The call came at 3:30am on April 16, 2012, and shocked everyone in the house.

Despite the early wakeup call, the surgery did not actually begin until 2:15pm. That was a long wait! My Dad, sister, Renee, and two friends arrived in town at 4:00pm, so I did not see them before my surgery. That made me a little sad but, for some reason, I was in a very peaceful mood and ready for things to get started. Thank goodness Paul and Kristi were there waiting with me!

My surgery lasted until 10:00pm. I required several pints of blood and had to be placed on a heart by-pass machine to relieve the stress on my heart. My chest cavity was left open for the next 24 hours so that the surgeons could monitor any clotting issues. The following Monday morning, April 18, I was taken off the ventilator and was able to finally see my family. My Dad and sister were in tears when they walked in the room and all I could say was, "Why are you crying??" We still laugh about that and many other funny and not so nice things I said while still on a lot of medications.

According to the surgeons, my surgery went very well and I appeared to be on the fast track to get out of the hospital. Well, my body had other ideas. I ended up with a chylothorax or "chyle leak", where my thoracic duct was leaking milky lymphatic fluid into one of my chest tubes. This pesky leak became a big problem requiring three subsequent surgeries to try to stop the leakage. On the first procedure, it was discovered that I have two thoracic ducts, which I was told was very unusual. After each of the first two procedures it appeared that the leak was repaired and then, within a day or so, the milky fluid would reappear. I went through at least two periods of several days when I could not eat at all while they hoped the leak would stop on its own. All I could have was sips of water with my meds and an occasional piece of gum. I tried to be nice to everyone who came in my room, but I really was ready to let someone have it! Finally, about two days after the third thoracic procedure, the chest tube fluid dried up and that final tube was pulled. What a relief!!! I was discharged one month after my initial lung transplant surgery.

I spent the next two months at an extended-stay hotel close to the hospital. They had a shuttle service that took my current caregiver(s) and me to my daily rehab and other hospital appointments. I had various family and friends rotating on a weekly basis

to stay with me. We called it the "changing of the guard". My St. Louis friends also helped in this rotation, especially when no one from home could be with me.

There were many ups and downs during these two months. During the first few days after leaving the hospital, I was terrified that something was going to happen to me and I would have to be rushed back to the hospital. I had gotten so used to the constant attention I received from the team in the hospital that it was scary to be away from them and a more secure environment.

I had quite a bit of physical pain, primarily from my secondary surgeries and the final chest tube site. It was very hard to find any comfortable position; it took many pillows! I tried to take as little pain medication as possible, but it was a necessity when I was trying to sleep. I also struggled with a lot of mental stress and anxiety during this time. I knew I should be ecstatic about having a successful transplant, but I had a very hard time getting happy. I contacted several post-transplant friends to help me through these rough times and they let me know that these were very common feelings.

With the continual stream of family and friends visiting, I eventually got out and about and saw much of what the great city of St. Louis has to offer. I have some wonderful memories shared with so many special people who were there to support me. Even with all the good times, though, I was very ready to move back to Kentucky when the big day arrived on July 15, just one day shy of my three-month anniversary.

My life since being back home has been continually improving. My $FEV_1$ is currently at 95% and I feel great. I went back to work full-time in October 2011. I am doing Jazzercise 3-4 times a week and love taking my dog for walks in my neighborhood. I am able to travel again, which is wonderful. I can clean my house, take out the trash, get the mail, go to the grocery, and go out to dinner with friends – all without coughing and struggling to breathe. It is so exhilarating!

I honestly don't think that if I had to do it over again I would do anything differently. And, as hard as parts of my recovery were, I would do it again. I would like to think I would try to be more patient with the speed of my recovery but, knowing my sometimes-impatient nature, that probably wouldn't happen. I am just so very grateful every day to my donor and family for all that their gift has done for me! ▲

*Lisa is 49 years old and has CF. She lives in Bardstown, KY.*

**BEATTY** *continued from page 1*

possibility to be a lifeline – and that was good enough for me.

Managing expectations, to me, means pushing myself within reasonable limits. It means being kind when I can't do something right away (or sometimes when I have to admit that I can't do it all), but it also means choosing every day to be optimistic about the possibilities. It means knowing the difference between "it's hard" and "it's impossible" and the difference between "I can't" and "I don't want to." It means that unlike what I experienced with end-stage CF, most of the time when I wake up sore and ache-y and feeling kind of crappy, I need to trust that I can push through it and that everything's going to be just fine. And of course it means being realistic when a problem simply isn't going away or can't be pushed through, and letting my doctors know – something that for me, personally, is always the hardest part.

Finally, it means acknowledging when my expectations were in fact wrong, and adjusting them accordingly. I'm two years out of transplant and haven't gained a pound, for example. It's not what I expected, and for me it is disappointing, but I have to learn to deal with it. I'm adjusting my expectations to try to be happier with what I have, even if it does mean that Boost Plus and I are going to have to stay friends for now. Blech!

I have a lot of friends out there currently facing the transplant decision. I remember that process – the fear and the hope, the excitement and the dread, the dreams of what would come later and the nightmares about what "could" happen at any given second.

So, for all of them and for all of you, here's what to expect from life after lungs:
Expect beauty.
Expect obstacles.
Expect to be happy.
Expect to shed tears.
Expect to learn lessons, some of them hard.
Expect to have to push yourself.
Expect the best out of everyone around you – including yourself.
Expect the unexpected.
Or, in other words, expect LIFE.
Happy breathing, beautiful people. ▲

*Piper is 30 and has CF. She lives in New York City. Her blog is at: http://amateroflifeandbreath.blogspot.com*

# Meeting Expectations

*By Andrea Eisenman*

While on the waiting list, I had very low expectations of what life would be like after transplant. I had met a few people in my lung support group who had had cystic fibrosis (CF) and had a bilateral lung transplant. They seemed to be better off than prior to transplant, but not one was telling me how wonderful it was or exhibiting fantastic health. I saw a lot of obstacles in post-transplant life for these people. Some were hospitalized frequently. Many were on IV antibiotics and experiencing infections and rejection. These were the people doing well!

I also met people pre- and post-transplant without CF and they did not always fare so well. Some were still on oxygen and some were so debilitated prior to surgery that they were still physically recovering in rehabilitation centers. But overall, they could breathe better than before their surgeries.

Needless to say, I knew I needed a transplant; my inability to breathe without the use of oxygen (O2) was there, my PFTs were around 15-17% and I had hemoptysis every day. During my desperate waiting period for lungs, my last 14 months on the waiting list (Allocation for lungs was different in 2000. It was based on time accrued, not level of illness.), I had come to a realization that if I died before or during surgery, I was not losing a lot. It seemed to me, trading CF for a transplant with all that comes with it, would be harder to manage. My choices were limited, so I was at the point of accepting this. I did not discuss this with my mom or friends as there was no point. Whatever happened would happen.

Then, a few days after a "dry-run" – being called in for lungs that were damaged – my mom and I went to the beach just to look at the water. We did that every so often, usually walking the shoreline, to appreciate the beauty of nature and to forget about what we did each day to keep me going. As we sat in the car just staring out onto the Peconic Bay, a rainbow started to form. As we watched it fully bloom, it started to mirror itself and became a double rainbow. Somehow, my mom and I knew from that point on, I would be ok. It gave us hope. It resembled two beautiful lungs!

One week later, I got the call that changed my life. My transplant happened and, from then on, my life was transformed into something I never expected–independence from an oxygen tank, no more coughing, and feeling like I didn't have CF any more. It was not as easy as all that. I did have some setbacks at first but, initially, I felt the hospitalization post-transplant went quickly and well. Still I went home worried and waiting for the other shoe to drop.

> "I feel so grateful for my transplant. It truly is a gift I appreciate every day."

Drop it did, in the form of seizures six weeks later. One of the immunosuppresants had given me swelling in my head that triggered two sets of seizures and eventually some brain damage—that explains a lot! Once that medicine was changed I did pretty well, especially after sinus surgery. If I had been healthier pre-transplant, I would have had to have sinus surgery before the lung transplant, but it was not possible with my PFTs. After that surgery, my head felt about five pounds lighter! I was also newly diabetic due to the prednisone usage. It was a lot to get used to.

All of this aside, I could not believe how great I felt! I barely coughed. I did not have to do a regimented rehab program. I was allowed to go to the gym and build myself up as I wanted. I biked non-stop initially on my stationery bike at home and then at the gym, walked on a treadmill, swam in my mom's pool, and just enjoyed not doing six to eight inhalations a day plus all the chest postural drainage, The Vest, and the Flutter device. I had time to go out into the world and just be.

Slowly, I started biking outside. It was so liberating to be able to get around on my bike and not be short of breath. Then my friend got me interested in playing tennis with her. As I got stronger, I took some group tennis lessons in Central Park. It was very different from when I had played as a kid. As my tennis improved, I was hooked and worked on getting even better. It turned out to be great exercise for my lungs. It was a stop and start motion that I was not getting when I biked or swam which are more constant movement exercises. I found that if I did have some phlegm in my lungs, after playing for an hour, I could huff it out without any effort. Tennis offered me a fun way to exercise that helped keep my lungs and mind clear.

It never occurred to me that I

would be playing tennis ever again. I feel so grateful for my transplant. It truly is a gift I appreciate every day. In that way, I try to give back and create awareness on how organ donation saves lives. That is why, every other year, I participate in the U.S. Transplant Games, now called the Transplant Games of America. It allows those who have had a transplant to take part in an Olympic-style event in varied sports such as swimming, track and field, bowling, table tennis, cycling, basketball and tennis.

Through this event, the focus is on promoting organ donation by showing transplanted athletes who are enjoying their donated organs, winning medals and living life every day. There is also focus on living donors and donor families. Without these selfless people, we would never have received a second chance.

This year the event was held in Grand Rapids, Michigan. I was fortunate to win a gold medal for singles tennis and one for doubles. I could never have done this without a lung transplant nor the drive to keep exercising to stay healthy.

When I was waiting, I did not see many good outcomes from lung transplant. In the last few years I have met many people who are doing so well it is impressive. I never expected to feel this good from a transplant. I am not indicating it is not without hard work and being compliant. But for me, it not only met my expectations but surpassed them. I highly recommend it for anyone in need of a lung transplant. May you all get your double rainbows. ▲

---

*Andrea is 47 and has CF. She is a Director of USACFA and is the Webmaster/Executive Editor of CF Roundtable. Her contact information is on page 2.*

# CFRI 2012 Dave Stuckert Volunteer of the Year Laura Tillman

Each year, at their educational conference, CFRI, Inc. recognizes a person who has been an outstanding volunteer. That person is awarded the Dave Stuckert Volunteer of the Year Award. Here is some of what was said about the recipient, this year.

The Boomer Esiason Foundation and Jerry Cahill have created clubs for those who have CF. Club 30 + is for ages 30 and older. Club 40+ is for those 40 and older. Our volunteer of the year belongs to the Club 60+.

Born in 1948, she was not diagnosed until age 47, and since the year 1995, she has been educating herself and others on how best to live a full life with CF: She is **Laura Tillman**.

Laura has been a director of the United States Adult CF Association (USACFA) since 2003 and now, as their President, leads this dynamic nonprofit in sharing the voices of adults with cystic fibrosis.

…. In [*CF Roundtable*] you will find her regular column, which lists varied and vital information that she has gathered from the Internet and other sources on a variety of CF topics.

Laura's involvement with the CF community goes far beyond her tireless dedication to USACFA. She has served many other organizations including the Michigan Pulmonary Disease Community, Inc. and the University of Michigan Medical School Mentoring Program for first- and second-year medical students. She has participated in podcasts, panel discussions, and also hosted webcasts to share her CF experience with others who have lung issues.

What some of you may not know is that Laura Tillman has been a volunteer for CFRI as well. She has dedicated her time and energy to CFRI conferences in numerous ways: as a past Conference committee member, she has helped to plan some of our educational conferences. She has participated in our panels, facilitated support groups, encouraged attendance and volunteered in the hospitality area.


**LAURA TILLMAN ACCEPTING HER AWARD AT THE CFRI CONFERENCE.**

Laura has been a regular columnist for our newsletter, *CFRI News* for the past several years. She distills information from a variety of sources to examine a particular CF topic in each issue.

Finally, we can call on Laura for important feedback on issues of the adult CF community. Laura Tillman is a caring CF volunteer who always is willing to assist anyone in any way that she can. Her energy is contagious and her positive outlook and encouragement have been personally inspirational.

Congratulations, Laura! ▲

POETRY CORNER

## TODAY

*By Jennifer Hale*

All the prayers, well wishes, positive quotes, positive thoughts do not take away this pain and disease. I still hurt, I still cry, I still beg for this to not be, but it is. All the hugs, calls, texts and hand holding will not dry my tears or heal my wounds. I still wake up each day with the pain and another day of trying to "get through". Some days are harder than others but the sun does come up each day and a new perspective and new chance to fight all over again... Sometimes deep in the night I feel I cannot take it and I cannot go on; but in the morning my perspective is different. So I wait for the morning sun to rise and new hope for a new day and new strength.....
August 2012

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

# UPCOMING SCHOLARSHIP INFORMATION

### Boomer Esiason Foundation Scholarship Program

**Deadline: December 15, 2012**

The Boomer Esiason Foundation's General Academic Scholarships assist CF patients pursuing undergraduate and graduate degrees. Grants are awarded quarterly on the basis of demonstrated need and academic accomplishment. They are made directly to the academic institution to assist in covering the cost of tuition and fees. This scholarship is for one year only.

The BEF Scholarship Program offers grants ranging from $500 to $2,500 and is awarded quarterly to students chosen by the board.

### Jerry Cahill You Cannot Fail Scholarship

**Deadline: April 18, 2013**

Boomer Esiason Foundation Volunteer Jerry Cahill created the You Cannot Fail program to challenge people to discover their own heroism, embrace the ups and downs of their life's journey, make a difference by sharing that journey with others, and celebrate the stories that make them unique. As a component of that program, BEF established the Jerry Cahill You Cannot Fail scholarship in 2012 to honor exceptional student-athletes with cystic fibrosis who, like Jerry, don't let the disease get in their way of living lives filled with purpose, passion, optimism and courage.

The Jerry Cahill You Cannot Fail scholarship is a $5,000 grant that will be awarded annually to one male and one female student. The April 18 application deadline marks the anniversary of Jerry's double-lung transplant.

### Sacks for CF Scholarship

**Deadline: January 11, 2013**

The "Sacks for CF" Scholarship is related to quarterback sacks made during the NFL season. The undergraduate and graduate award is made annually to 30 people who strive for therapy adherence and academic success. Amount: $3,000 to $10,000.

Applications and all documentation must be received by Friday, January 11, 2011.

The names of scholarship winners will be announced on Super Bowl Sunday, February 6, 2011.

Students can learn more about our scholarship programs and the application process by visiting:

http://esiason.org/thriving-with-cf/scholarships.php.

# Rally 'Round CF Roundtable

**USACFA, PO Box 151024, Alexandria, VA 22315-1024**
**Voice mail: (248) 349-4553**
**E-mail: cfroundtable@usacfa.org**

## Welcome to our annual fundraising drive!

We are grateful for the subscriptions and donations from so many people. However, we are feeling the effects of the economic crisis and are looking to our community for some support.

### Fun Facts about CF Roundtable

- Started in 1990 by adults with CF
- All work is done by volunteers
- We currently have over 1300 subscribers
- No one is turned away because they are unable to afford a subscription
- People in ten countries subscribe to CF Roundtable
- Articles from CF Roundtable have been reprinted (with permission) in other countries

### Money Facts

- It costs approximately $5.50 to print and mail each copy
- Out of our 1300 subscribers, only 500 are currently paid up
- The subscription rate has increased only once since 1990

### It's So Easy for YOU to Help Keep Us Going Strong!

We would be grateful for any donation you can send in addition to your annual subscription.

***Want a fun way to choose your donation amount?***

- Donate your age in dollars—This is especially fun if you have CF, because it is a great way to celebrate and honor every year!
- Pledge just $5.50—That will cover the cost of one copy. Or, if you can, send in $11 for two copies!
- Give an additional $15 to cover someone else's subscription fee.
- Share any denomination you choose; we appreciate all support whether it be $1 or $1,000!
- Ask your friends and family to help you and send in a big donation.

*Any donation above and beyond the $15 annual subscription fee is welcome. Every little bit helps us continue our mission of reaching out to adults with CF.*

***Remember USACFA is a 501(c)(3), nonprofit organization, so any donation beyond your annual $15 (actual cost) is tax-deductible.***

**Detach this portion and mail your donation to: USACFA, P.O. Box 151024, Alexandria, VA 223115-1024**

Name _____ I have CF _____ Yes _____ No

Address _____ City _____ State _____ Zip Code _____

Phone _____ Email _____

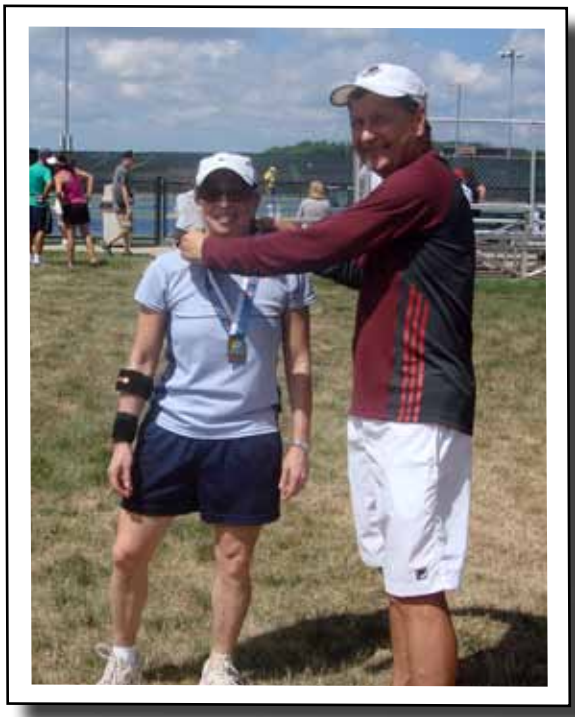
I choose to donate: _____ (Please make checks payable to USACFA)

**The USACFA Directors thank you for your continued support!**

# FROM OUR FAMILY PHOTO ALBUM...

MICKEY HART AND PAUL ALBERT AT THE TRANSPLANT GAMES OF AMERICA.

PIPER BEATTY, WEARING HER 'FIGHT CF' GEAR FROM TEAM BOOMER AND THE CFF, SUPPORTING THE SEARCH FOR A CURE AT A LOCAL FUNDRAISER.



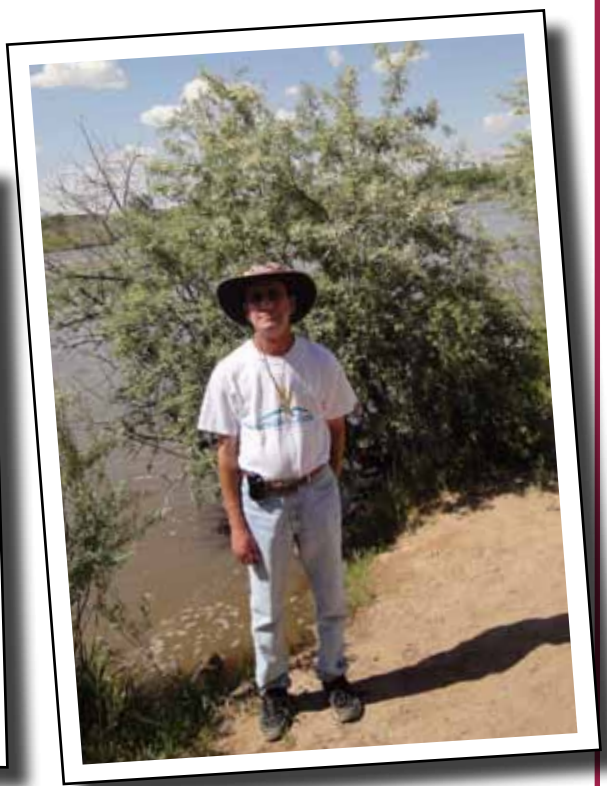
ANDREA EISENMAN RECEIVES HER GOLD MEDAL FROM HER TEAMMATE, JIM NELSON, AT THE TRANSPLANT GAMES OF AMERICA.

RACHEL MAUGER VISITING NIAGARA FALLS, NY.

SIMON AND MITCH GREENBERG.

ANA STENZEL, ANA MODLIN, LISA CISSELL AND ISABEL STENZEL BYRNES AT THE POOL AT THE TRANSPLANT GAMES OF AMERICA.


DEBBIE (POST-TRANSPLANT) AND LOUIE AJINI AT A EUCHRE FUNDRAISER FOR HER TRANSPLANT FUND.



PAUL FELD NEXT TO THE RIO GRANDE NEAR AN ALBUQUERQUE NATURE PRESERVE, IN NEW MEXICO.

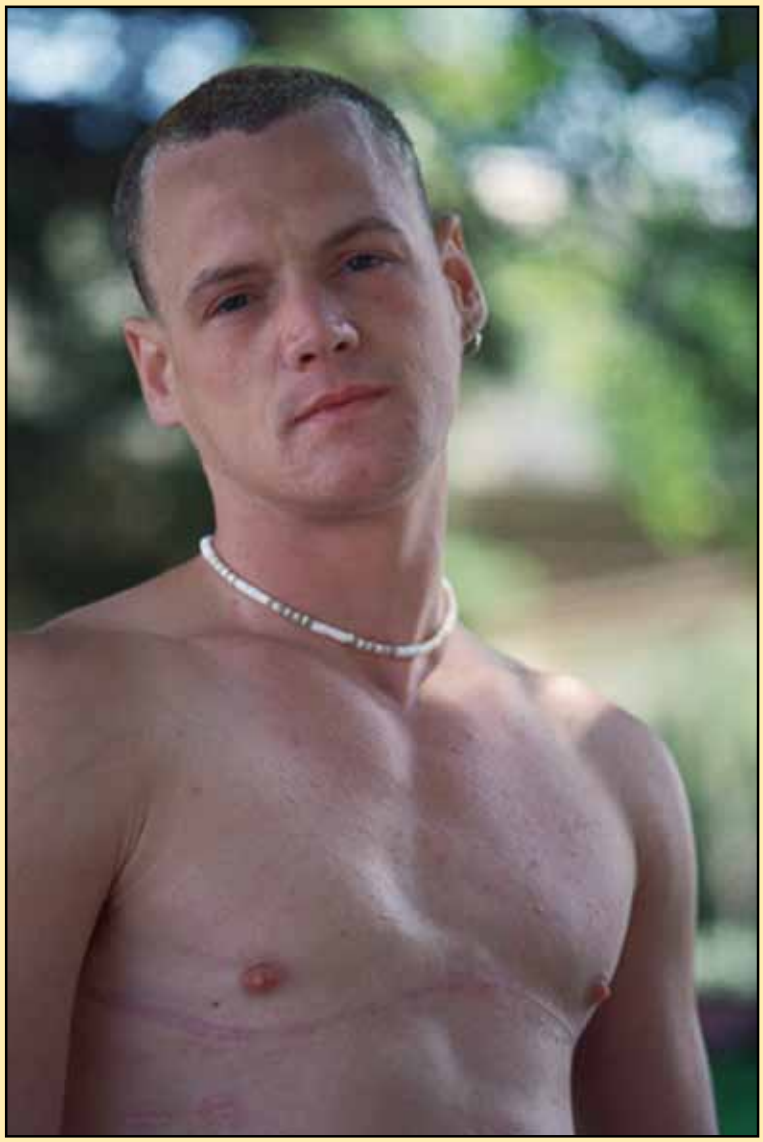


PHOTO BY MARGARET MYERS

## Scarred for Life

*When you look unto my portrait what at first do you see?*
*A picture of health and strength...*
*Or a scar that illustrates me?*

*I've tried to embrace it and call it my own.*
*But when I look into the mirror...*
*I feel so alone.*

*For with this scar I fear the worst.*
*A life without love...*
*To which I'm cursed.*

*Confidence and attraction I once possessed.*
*A wealth of self- esteem...*
*Lost to the scar upon my chest.*

*Passage of time brings greater strength and wisdom.*
*While with these new lungs I inhale...*
*Comes a wonderful breath of freedom.*

*Acceptance has settled*
*My world is all brand new*
*I now see things in an entirely different view*

*It consumes me with pain no longer nor fills me with rage*
*A symbol of victory and survival...*
*My scar is my Badge of Courage for which I will hold on to as I grow to an improbable age.*

*So when I look unto my portrait what at first do I see?*
*Not just another scar...*
*But a Man that illustrates me.*

*-A. Diprofio, 2002*

---

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

## POETRY CORNER

*Editor's note: although we rarely publish anything that is written by someone who doesn't have CF, we make an exception for this young (age 8) man's reflections on his father's (Mitchell Greenberg) bilateral lung transplant.*

# The Transplant

*By Simon Greenberg*

(labored breathing sounds in and out)

I am in North Carolina waiting for the thing
to be done.
My dad is in the bed... anything to be done??
Shots... OW OW OW.
What a day, waiting;
My dad feeling well now;
Good- wow!
The Doctor is in the house!!!
The blood test will be done now, Get over here!
Come on! Come ON!

(Normal, unlabored breathing in and out)

**TILLMAN** *continued from page 13*

the most common cause of cystic fibrosis (CF). The most common CF-causing genetic mutation, known as delta F508, disrupts the process whereby the CFTR protein is folded into its correct shape and shipped to the membranes of cells that line the airways and other organs. Most of the defective CFTR protein is mis-processed and gets degraded. The researchers investigated the role of microRNAs – small non-coding stretches of RNA – in regulating expression of CFTR. They discovered that one particular microRNA, called miR-138, helps control the biosynthesis of CFTR by regulating a network of genes involved in the production and processing of the protein. The study shows that miR-138 acts on the other genes to orchestrate a cellular program that increases production of CFTR and increases the amount of the protein that is transported to the cell membrane where it functions as an ion channel. The researchers found that when the gene network was activated by miR-138, it not only increased the amount of the mutated protein, but also partially restored the protein's function. By manipulating the microRNA network, the researchers were able to change the fate of the misfolded CFTR from being degraded in the cell to functioning as an ion channel in the cell membrane.

http://tinyurl.com/cgwzv6u

## FYI

**Recurrent Clostridium difficile colitis in cystic fibrosis: An emerging problem.** Katarine Egressy, Michaelene Jansen, Keith C. Meyer. Journal of Cystic Fibrosis. Published online 21 June 2012.

*Continued on page 27*

# How Transplant Changed My Life for the Better

*By Rachel Mauger*

RACHEL MAUGER HIKING AT RICKETTS GLEN STATE PARK IN PENNSYLVANIA.

It seems like a lifetime ago that I was anxiously awaiting a new pair of lungs and sitting here writing another article, "*How to Survive the Road to Transplant*," which was published in the Summer 2009 edition of *CF Roundtable*. I can hardly believe that now I sit here planning to celebrate, later this month, the third anniversary of my bilateral lung transplant.

In the article published in 2009, I shared with readers my experience of going through the course of becoming actively listed for transplant and offered my suggestions for how to survive this intense process physically, mentally, and emotionally. As I prepared to write this new article now from the "other side," I struggled with how to convey to you the reality of the challenging journey I experienced during my transplant and the six months immediately thereafter, without overshadowing the truly AMAZING positive transformation my double lung transplant has brought to my life. After many drafts and much consideration, I decided to focus this article entirely on just the latter part. My hope is that by sharing with you just some of the many ways my life has changed for the better, that knowing what you, too, can stand to gain once you indeed reach the "other side," will give you the inspiration and courage to survive the toughest days of your own journey before, during, and immediately after transplant.

Breathing: By the time I received my transplant, my $FEV_1$ was at 17% and I required 2-3 liters of continuous supplemental oxygen to keep my saturation stats above 92%. However, like so many other people with CF, I was a master at adapting to my ever increasingly restricted breathing and I did not even realize, really, just how bad my breathing was until I took that first real breath with my new healthy lungs.

By my first PFT post transplant, which was done about three weeks after my transplant, my FEV1 was already up to 54%. At my best thus far post transplant, I was able to achieve an $FEV_1$ of 99%, which occurred about six months after my transplant. Despite a bit of a rough recovery from my transplant initially, I can attest first hand that no matter what was thrown my way medically speaking – including something as severe as a weeklong stay in the ICU with multi-system failure – was worlds easier to deal with when you can actually breathe while dealing with it! Although not quite as good as I was at just six months out, I continue to have a normal reading PFT with an $FEV_1$ between 83% and 86% and do not require the use of any supplemental oxygen at any time.

Coughing: At my sickest, I don't think I could go a minute without coughing. Even when it wasn't quite that bad, I still coughed all the time and would spit out all kinds of gross crap that caused a terrible taste in my mouth and lead to constant bad breath. I remember strangers thinking I had a "smoker's cough" and hating that I felt like I was always interrupting a movie or someone's presentation when I attended an event, because I just couldn't keep from coughing. I remember stepping out in the cold or just walking up a flight of stairs leading to an intense coughing fit.

To those of you for whom this sounds familiar, it will be hard for you to believe that initially after transplant I had to force myself to cough at the direction of the transplant team, in order to keep my new lungs clear. It may be even harder to believe that I literally NEVER cough now. This initially took some getting used to, not only for me, but also for my family who would walk into a room and not even realize I was there at first because suddenly I was so quiet all the time! Not to worry, though, as I soon filled this quiet with often non-stop, high speed chatter now that I actually had the breathing capacity to support such rapid conversation without becoming winded! Now that I have grown used to and quite enjoy this non-coughing thing, it actually catches my attention if I cough even just once!

Sleep: Before transplant, I was tired all the time and would sleep 10-12 hours a day in order to have enough energy just to function at the most basic level and yet, whenever I tried to sleep, I slept terribly. In order to get any sleep, I would have to find just the right position where things would settle and I could stop coughing and actually catch a few zzzz's before a coughing fit would wake me back up.

Without the coughing, I am now able to sleep so much better and, in turn, require only about eight hours of sleep at night to feel fully rested. I'm able to sleep comfortably and quietly on both of my sides as well as my back and I rarely need any nap let alone the couple-hour-long naps I required before. My energy has increased dramatically and I have been able to return to my very active lifestyle.

Gastrointestinal Issues: Prior to transplant, I always felt nauseous and my stomach hurt constantly no matter what I did. I was a picky and light eater my entire life and my mother was always trying to shove extra calories down my throat. I had to take Miralax® and Colace® multiple times daily on top of my regular digestive enzymes just to keep things moving as they should. At my continued insistence that something was just not right with my digestive system, I had every gastrointestinal test under the sun done to no avail to try to determine the root of my constant stomach problems. Miraculously, these issues literally all "disappeared" after my transplant. My gastroenterologist explained it to me like this: when you can't breathe, your body really cares about little else – even eating – and the little energy your body has goes to working to supply your body with oxygen rather than to digesting food properly.

I now enjoy food and eating for the first time in my life. In all honesty, my mother says that one of the hardest changes for her to get used to after 26 years of fighting to get me to eat all the time was seeing me willingly clear off my dinner plate and ask for seconds or see me hunting in the fridge for more food less than an hour after finishing a meal. I'm 5'2" and by the time I was transplanted I was severely underweight at only about 80 pounds. My new interest in food and eating however made gaining weight easy for the first time in my life and I was able to put on 50 pounds since then. I am now easily able to maintain a healthy weight for my size. Ironically, one of my biggest challenges is actually for the first time ever having to watch what I eat and lay off some of the high calorie, high fat foods that were staple components of my diet over the years of trying to keep my weight up!

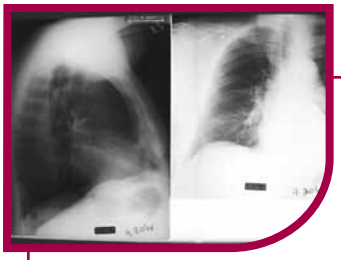
Daily Maintenance Regimen: Next to my breathing, this is without a doubt the area where I have experienced the most dramatic change, for which I am ever so grateful. At my sickest, I would spend 4-8 hours a day doing nebulized treatments, chest PT, nasal rinses, oral medications, insulin regulation etc. and this doesn't even include the time I spent exercising and napping! By the time I finished all my treatments, there was little time left for having much of a life; not that I was feeling up to much of one anyway.

Things like just taking a one-day trip anywhere became cumbersome and exhausting as all the equipment I required throughout the day looked like I must be packing to go somewhere for a week. As such, among other things, my daily regimen decreased my tendency to go anywhere locally let alone travel long distances, one of many things I loved and could no longer do!

Now on the other side of things, unless I am sick and requiring antibiotics which is pretty rare, my daily routine now takes me maybe 15 minutes total (not counting exercise) and consists only of my nasal rinses, checking my stats each morning, my insulin regulations, and taking a whole lot of oral medications 4-times-a-day. When people are shocked by the number of oral meds they see me take each day, my reaction is usually something to the effect of, "Are you kidding? This is so easy!" Popping a few handfuls of pills seems like such a minor inconvenience in comparison to all I used to have to do to keep my body going from day to day. Oral meds are also extremely portable and this change has helped contribute to my ability to resume things like traveling and my very active lifestyle.

Regularly applying suntan lotion with an SPF of 100+ has also become a regular part of my routine because

*Continued on page 29*



# A DEEP BREATH IN
# New Lungs - Part 1

*By Debbie Ajini*

I am going to tell you the end of this story first because it is a happy one. I received a bilateral lung transplant on July 28, 2012, at 12:08 am at University of Pittsburgh Medical Center (UPMC). I am home and doing well!

### Here is my story of how I got here...

I have posted about my health and its decline over the years here at *CF Roundtable*. I have been using oxygen ($O_2$) since 2005 and have seen my PFTs slowly dip from the mid-30s to the high-20s. I began going to UPMC for transplant evaluations in July 2008. I always was just healthy enough to not be listed. My life was filled with treatments and exercise to stay as healthy as possible. Then two to three times a year I would do a two-week course of IVs. Some were harder to bounce back from than others. I managed to have a decent quality of life. Although, looking back, the definition of "quality" changed between January 2005 and April 2012.

I got an infection in May of this year (2012) and, from the start, it seemed different, more stubborn. I did a three-week course of IVs at home, then I went in the hospital for 10 days (where I cultured positive for C. difficile.) During the next three weeks at home I continued to deteriorate. While I did not have fevers, I was extremely weak, using more oxygen (up to 6 liters) and I needed help with every task.

It was during this time we decided to actively pursue getting on the list. Imagine our surprise when we found out that the prior approval from our insurance had expired. So now we had to scramble for approval. In the meantime, I kept getting sicker. We decided to go see my doctor in Pittsburgh. He immediately put me in the hospital for three weeks.

During those three weeks the insurance approval came through and I was put on the list. To say we were relieved would be an understatement. What was weird was that I had spent so many years trying to stay healthy and stay off the list, but I knew I had it to fall back on. Then when there was a chance my insurance wouldn't pay, I was afraid I wouldn't get the surgery and that I had waited too long. While I was in the hospital for those three weeks, I got healthier and stronger in that visit - but not better. By the time we left the hospital on July 27, 2012, I was using 8 liters of oxygen!

### Getting the call

Getting the call is my favorite part of my story. Well, one of my favorites. On our way home from Pittsburgh on Friday, July 27, I remember specifically saying two things. The first was, "I feel really good, the best I have felt in over six months." I also asked my husband, "Do you know the Pittsburgh area code so that when it shows up on your phone you know to answer it?" He did. It is 412.

LOUIE AND DEBBIE AJINI BEFORE TRANSPANT SURGERY.

A half hour later, two hours from Pittsburgh, *my* phone rang with a 412 number! I screamed to Louie, "It's a 412 number!" He calmly told me to answer it. I did and I was told to not drive any farther, to not eat or drink anything because they may have lungs for me, but that I was the back up. So we pulled into a service area on the Ohio Turnpike and waited. What a surreal 20 minutes.

Then the phone rang again. I was the OFFICIAL backup, but they believed I would actually get the lungs based on size. We turned the van around and headed back to UPMC where we had been discharged just three hours earlier. During that car ride there were tears of joy and phone calls made to family and friends. It was so surreal. I couldn't believe this was *maybe* going to happen. It all seemed so fast. Even now, three months later, I still can't believe what I went through.

The next few hours went by fast and slow at the same time. We checked in and did some pre-op work. We called friends and family. We waited. We talked. We cried. Despite our fears, Louie and I were ready for whatever lay ahead.

Some of our family came and then it was time to go wait by the OR. We weren't sure the lungs were good to go yet, but since I was the only one in the holding area we knew they were mine. I signed paperwork and then suddenly it was time to go. I wasn't quite prepared to leave my family so soon. I imagined a TV goodbye with hours of

chatting, sharing stories and crying. Yeah, there was no time for that! There were quick hugs and kisses (Louie got a longer hug) and as I was wheeled away Louie played our theme song for this journey, "My Body" by Young the Giant (Look it up, it's a good one!) I got into the OR, made some chit chat with the staff for a few minutes and next thing I know I am in ICU. I was groggy and wasn't sure I had the surgery. Then through a haze, I saw Louie silhouetted in the dark room, leaning in and saying, "You did it. The surgery is over. You are doing great. I am so proud of you. I love you." Some of the most beautiful words I have ever heard in my whole life.

As you know that is where a whole other journey begins. Look for my article in the next issue where I recall those days of recovery and how my life is now. ▲

*Debbie is 42 and has CF. She is a Director of USACFA. Her contact information is on page 2.*

**TILLMAN** *continued from page 23*

C. difficile colitis can cause life threatening illness in patients with CF, and symptoms may be subtle and/or atypical and lead to significant delay in diagnosis. Patients with recurrent C. difficile colitis are at high risk of fatal outcome, and empiric therapy should be considered for patients with previous C. difficile colitis even in the absence of disease when broad-spectrum antibiotics are given to treat bacterial infection.
http://tinyurl.com/9agnhsz

**Quality of life in clinically stable adult cystic fibrosis out-patients: Associations with daytime sleepiness and sleep quality.** Anna Bouka, Henning Tiede, Linda Liebich, Rio Dumitrascu, Cornelia Hecker, Frank Reichenberger, Konstantin Mayer, Werner Seeger, Richard Schulz. Respiratory Medicine. Volume 106, Issue 9, Pages 1244-1249, September 2012

In clinically stable adult CF outpatients self-reported daytime sleepiness and poor sleep quality are more common than in age and sex-matched healthy controls. In addition, impaired sleep quality is related to reduced disease-specific quality of life in CF.
http://tinyurl.com/d333ew5

**Molecular typing and antifungal susceptibility of Exophiala isolates from patients with cystic fibrosis.** Ann Packeu, Patrick Lebecque, Hector Rodriguez-Villalobos, Anca Boeras, Marijke Hendrickx, Jean-Philippe Bouchara and Françoise Samoans. J Med Microbiol September 2012. vol. 61 no. Pt 9 1226-1233

The black yeast Exophiala dermatitidis is a frequent agent of colonization of the lungs of patients with cystic fibrosis. Variations were seen in the susceptibility of studied isolates to antifungals but most of them exhibited low susceptibility to amphotericin B and although some patients were successively colonized by two distinct genotypes, most of the isolates were distributed in patient-specific clusters. This phenomenon may be due to genomic variations of E. dermatitidis in the lung environment of CF patients. These results are typical of colonization of the airways of patients by a poorly distributed environmental fungus, which occupies particular reservoirs that need to be defined.
http://tinyurl.com/8qxke6v

**Diabetes before and after lung transplantation in patients with cystic fibrosis and other lung diseases.** Bellevan Meerkerk, G.; van de Graaf, E. A.; Kwakkel-van Erp, J. M.; van Kessel, D. A.; Lammers, J.-W. J.; Biesma, D. H.; de Valk, H. W. Diabetic Medicine, Volume 29, Number 8, 1 August 2012, pp. e159-e162(4)

Diabetes diagnosed before lung transplantation has a negative effect on survival after lung transplantation in patients with cystic fibrosis. Pre–existing diabetes is common in patients with cystic fibrosis, in contrast to patients without cystic fibrosis. Development of new–onset diabetes after transplantation is similar in both groups.
http://tinyurl.com/bv7fc5w

**State of progress in treating cystic fibrosis respiratory disease.** Patrick A. Flume and Donald R Van Decanter. BMC Medicine 2012, 10:88

Since the discovery of the gene associated with cystic fibrosis, there has been tremendous progress in the care of patients with this disease. New therapies have entered the market and are part of the standard treatment of patients with CF, and have been associated with marked improvement in survival. Now there are even more promising therapies directed at different components of the pathophysiology of this disease. In this review, current knowledge of the pathophysiology of lung disease in patients with CF is described, along with the current treatment of CF lung disease, and the therapies in development that offer great promise to patients.
http://tinyurl.com/9kmt9wg

*Continued on page 34*

# TRANSPLANT TALK

## Hair Today, Gone Tomorrow

*By Colleen Adamson*

Hair can be a big part of who you are, and what you and others think of you, whether we like it or not. My hair and I have been through many stages over the years. My hair started off very curly and blonde when I was a child. Then it became straight and darker. Perms were a standard throughout high school and college, of course (the '80s!), and the perms made my hair lighter - a strawberry blonde color. I loved perms because they made my thin hair fuller and my hair was easy to style. Unfortunately perms went out of style and I ended up with flatter, darker hair again. The slightest bit of humidity, rain, wind, you name it would ruin any kind of style my hair had.

Since my lung transplant in 1998 and kidney transplant in 2006, I have had several skin cancers, all caused by immunosuppressant drugs, not from being out in the sun. Last year, I ended up with an aggressive form of squamous cell skin cancer on the top of my head. I have never had an aggressive skin cancer before, so this was pretty scary. My oncologist removed the cancer on July 5, 2011. The site was approximately 10 x 13 centimeters, pretty big for my head! My doctor put a skin graft from my thigh on the top of my head to cover the site.

Then came the radiation. I had six weeks of radiation to make sure any lingering cancer cells were killed. My hair all fell out and most of it did not come back. I have a friend who had breast cancer, and she had gorgeous wigs so I went to the same shop for my wig. I was amazed and pleasantly surprised at how much wigs look like real hair when I had them on. At a party recently, someone actually asked me how I got my highlights to look so good and where did I go to get my hair done! Anyway, the wigs didn't have bangs (a must for me!), so I went one last time to my hair stylist (who had been cutting my hair since 1993), and she cut the bangs in and trimmed them a bit. My friends, Sam and Theresa, were with me and they were so supportive, telling me how great I looked. They made me feel so much better about wearing a wig. It's not exactly what one would want to do, but for me, it's now a reality. Since I have a skin graft from my thigh on the top of my head, I will never have hair there. I will always have to wear a wig from now on.

In general, I try to look at the bright side of things, find the positives. Now that I have a wig and no hair, I don't have to buy shampoo, conditioner, hair spray, and hair gel. Think of the money I'm saving! My hair dryer and curling irons are no longer cluttering up the bathroom and using electricity. It's also very nice to be able to take it off when it's hot out, which happens often here in Virginia, and wear a hat instead. I get to work a half hour earlier (and get home half an hour earlier) than I used to because I don't have to spend any time washing, drying, and styling my hair. I no longer worry about humidity, rain, winds, wearing hats etc. Nothing can affect my hair style! My (bald) next door neighbor, whom I've known for only a few months, told me that "Hair is overrated." That made me laugh. My friends tell me they wouldn't want to go through what I've gone through, but they really like the idea of wearing a wig and not having to deal with their hair. Me too!


COLLEEN ADAMSON

My family and friends are very supportive, but it's not just them. People in my office tell me how nice my hair looks, and some of them I don't even know. People from my church tell me the same thing, sometimes at church and one time in the grocery store! I'm so thankful to have such wonderful people in my life. It especially amazes me when people I don't even know compliment my hair, wanting to be supportive.

It's been almost a year now that I've been wearing a wig, and it's no big deal, to the point where I don't really think about it much. I'm very open about it and happy to talk about it if anyone asks. This way I am able to promote taking care of your skin and seeing a dermatologist. When talking to people, my wig can be an avenue to get the message out about protecting skin from the sun. So I hope that when people who know (and read!) my story and see me wearing my wig, they remember to call their dermatologists, and wear sunscreens and hats when outside! ▲

---

*Colleen is 43 and has CF. She is a Director of USACFA and is the Treasurer. Her contact information is on page 2.*

on top of being a fair-skinned redhead, my increased susceptibility to the sun caused by some of the medications I have to take means I now burn through car windows and even multiple layers of UV protective clothing. However, I don't let this stop me from enjoying many outdoor activities; I simply take a few extra precautions to protect myself from the sun, a very small inconvenience for all that I have gained.

Lifestyle: As I faced transplant, another very difficult adjustment for me on many levels was the fact that I could no longer do everything for myself and was forced to accept the fact that I needed help. This meant that, after eight years of living on my own, I had to move back in with my family. I also grew very frustrated that my body couldn't keep up with my mind and my preferred active lifestyle. In all honesty, such frustrations actually helped make facing transplant that much easier as I felt like I had no quality of life anymore and, as such, had nothing much to lose if things did not go well. I was no longer able to do any of the things that made life enjoyable and meaningful to me. I longed to feel useful and for my life to be purposeful beyond creating what I felt was more work and stress for all my loved ones.

I'm thrilled to report however that thanks to my new set of lungs, I've been able to return to my very active lifestyle and my adult life. I was strong enough and back on my feet enough financially to move back out on my own about two years after my transplant and I have regained my own space and independence. Even though I was forced to find a totally new career path, I have been back to work full-time at a 40+ hour-a-week job I enjoy, for two years now. I found the confidence to start dating again and have been lucky enough to be with my current boyfriend for just under two years.

I'm also able to not only travel but also fly again, a luxury taken away from me several years before my transplant, and I have resumed traveling for both work and pleasure. In the last three years I have been everywhere from Las Vegas to Denver to Atlanta to Niagara Falls and many more places! I also have swung on and completed a catch on a flying trapeze, learned to both water and snow ski, completed a 7 mile, 1000 foot elevation change hike, and finished my first ropes and zip line course among many other vigorous activities. I also have gone to the Macy's Thanksgiving Day parade, seen my sister earn both her Bachelors and Masters degrees, ridden on the back of a motorcycle and got to meet my best friends' first child; just some of the many cherished experiences I've been privileged to share in and otherwise would have missed out on if it weren't for these new lungs!

Outlook on Life: It's not easy to put into words and truly convey all that has changed in my life from three years ago and I continue to be in awe of how far I've come whenever I stop and think back to what my life used to be like. Although I'm not confident that I've been able to truly capture the transformation my life has taken in this article, I do hope however that, in the least, I've given those currently waiting on the transplant list hope that there is a possibility for a better future. I know not everyone who goes through transplant is as fortunate as I have been and I am thankful everyday that my strict adherence to the post-transplant rules that you will learn as you go through the transplant process has helped to make my experience a successful one.

It is still hard for me to believe that it has really been two-and-a-half years since I required any sort of hospitalization or treatment with IV antibiotics; two things I can't say I miss in any way, shape or form! I sometimes even find myself feeling guilty that one of the most difficult things I deal with now is the fear of losing every aspect of my life that seems so good right now and being forced to return to the "sick life" I hated so much. I rationally know it is more a matter of "when" than "if" I will return to this state, but I intend to continue to do everything in my power to make that "when" as far from now as possible. I make a conscious effort each day to keep such worries tucked to the side of my mind just enough so as not to make me afraid to live my life to the fullest but at the same time conscious enough to serve as a reminder not to take anything for granted and to appreciate and take advantage of every moment of every day that I am lucky enough to have, however many that may be.

Once you've been through transplant, it becomes impossible to look at the world in the same way as you did before, as you will have a newfound appreciation and gratefulness for every little thing. I can honestly say that thanks to my bilateral transplant, I am enjoying the best quality of life, as well as the best physical health, that I have ever experienced. Given the chance to do it all over again, I wouldn't hesitate for a second despite the challenges and obstacles I have faced throughout the process. Transplant has, without a doubt, exceeded my wildest expectations and allowed me opportunities that I otherwise would not have had or been capable of. I am forever thankful to my donor and the donor's family for such a tremendous gift that I will never be able to repay. I look forward to many more healthy years and new adventures to come! ▲

---

*Rachel is 29 and has CF and CFRD. She received a bi-lateral lung transplant at New York-Columbia Presbyterian Hospital on September 26, 2009. Once an elementary teacher, Rachel now works as an Executive Assistant at a large dental practice. She can be contacted at: rstout@kent.edu.*

# COUGHING WITH A SMILE...

## The Numbers Game

*By Jennifer Hale*

What is in a number? For those who suffer from disease a number could mean more medication, decline in health or time to make changes in your current regimen. A number can also bring hope. A number can indicate all is well in your body and you're on the right track. But there are times when the number is not where it is supposed to be and it is directly affecting how you feel and your prognosis. Numbers do not always tell the tale, but they are an indicator for me - a barometer to measure and compare my statistics of past tests. My body and how I "feel" tell me what my true number is. Am I feeling good mentally and physically? Am I able to get through my day with a smile on my face and feeling good? How can I feel "good" when my lung function is only 39%? How am I functioning? I suppose we all find out what our parameters are and adjust our sails to the wind of change. Change is a big word in the life of those who suffer from disease. Change is always occurring and I notice I am always adjusting for each change. Sometimes it is daily, sometimes it is weekly and even, sometimes, it can be hourly. But I can adjust with each change and it is a chance to turn it all around. Sometimes I cannot turn it around even if I try my hardest, but tomorrow is a new day.

Recently I had to undergo a Toupet Fundoplication or in layman's terms, an esophagus wrap. I had severe acid reflux and it was detected by my sputum culture and decline in lung function. My numbers were dropping and GI bugs were ending up in my sputum cultures; hence in my lungs! That is not supposed to happen and after doing several Acid Reflux tests, it was determined that I needed this surgery.

I was not crazy about getting it done because I never had surgery before, so this was all VERY new to me. What clinched it for me is when the surgeon said to me, "Is it fair to say that if a CF patient lives long enough they will need a lung transplant?" Through my tears I said, "Yes, that in my opinion is correct." He then proceeded to explain that in order to preserve the lungs I have now and to protect my "new" lungs in the future, if and when, I go down that road, then this surgery is necessary. For me, I thought to myself, I want to keep these old lungs for as long as possible. So if I am going to give myself any fighting chance to do that, then this surgical procedure must be done. And if and when I get that miracle of new, bright pink lungs, then this surgery will allow those lungs to function at their utmost capacity. So in the end it was a no brainer. Toupet Fundoplicaton, here we come! I say we because what happens to me happens to my husband, who is the light of my life.

> *"Change is always occurring and I notice I am always adjusting for each change."*

MARK AND JENNIFER HALE.

On a side note, my husband stayed with me in the hospital all night long for two nights. He slept on something they called a bed but, instead, was that of a park bench. He pushed my pole down the hallways and gowned and latexed up when sitting in my room - ALL DAY LONG! Poor guy got a blister on his hands from wearing the latex gloves all day long. He is my Prince Charming! As I lay there in bed in pain, unable to care for myself and be an advocate for myself, my husband, my love, was my voice, my hands, my legs, my heart. He is truly my EVERYTHING.

The procedure is a tough one but manageable with pain pills! Got to love modern medicine! The procedure calls for the surgeon to wrap part of your stomach around the end of your esophagus so the acid cannot make it up the esophagus and seep into your lungs. The first two weeks were no

picnic. The main problem is having cystic fibrosis while undergoing the surgery. I was unable to cough for two days and treatments were not the greatest. You see, it hurt so very bad to cough! It felt like my stomach was ripping apart. It hurt so bad, even with the pain meds, that it brought me to tears. Luckily, and thankfully, the pain that caused tears lasted only a few days; then it was just pain with no tears! I know that might not sound so much better but when you are going through it there is a big difference between pain that causes you to cry and pain that just causes you to wince. I will take wince. Rather I will take no pain at all! I am a baby! A 40-year-old, big, ol' baby. But, hey, I have been through a lot and continue to go through a lot so pass the Sippy cup! LOL! After two weeks it got a lot better and at the three week mark I was able to start eating solid foods. Weeks of shakes, jello, pudding, apple sauce and soup were getting old. I needed something that sticks to your ribs. Once starting food my stomach did not like it too much. I am still having diarrhea issues, gas, bloating and pain. Never fear. It is all getting better; it is just a very slow process. At the six week mark, things are a ton better! I am eating pretty much anything I want; slow with small bites and pain is very minimal. The surgeon says it takes about three months before one can say they feel back to their good old self. November never looked so good!!!

My hopes are that I can recover from this with flying colors and I can get my 39% $FEV_1$ lung function raised! It is scary to be that low and the demands that I put on myself to function like when I was $FEV_1$ 65% are just unrealistic. I am not that person anymore, but that does not mean I cannot be that person again or close to it! I am a firm believer in exercise and I hope to be able to start that soon, so I can work on this $FEV_1$. I have to say that since I have not been able to exercise, I have been very diligent about doing an afternoon treatment and with using this plastic apparatus the surgical team gave me for my lungs. It is this plastic, hand held "thing" on which you take a deep breath and make a white cylinder rise. I find it really is great for working your lungs and taking deep breaths. It has helped during this time when exercise is non-existent and I plan to continue with this apparatus even when I have accomplished my goals.

Recovery is slow. Patience is needed and there are highs and lows. During my lows I wrote a poem called TODAY that you can read in the Poetry Corner section of this *CF Roundtable*. I also have the poem posted in the BLOGS on the *CF Roundtable* website. (http://www.cfroundtable.com/2012/09/07/today/) I hope it helps you or someone you know as much as it helped me writing it out on paper.

Well, until next time readers. Hopefully I will be able to report that things are on the up and up! ▲

---

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

# Information For People Who Travel On Airlines

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

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

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

# IN THE SPOTLIGHT
## With Paul Albert

*By Andrea Eisenman with Jeanie Hanley*

Having a transplant can be transformative, but it is not all fun and games. And yet, Paul Albert makes it seem easy in his attitude and the way he presents himself. I find him to be modest, honest and funny.

Paul was someone I had run into at the transplant games for the last few years. Most recently in 2010, we were staying in the same hotel and caught up with each other on the shuttle from the airport to our hotel in Madison, WI. It was there that I learned how long it was since he had been transplanted and, right away, it gave me hope. I was happy to know someone with CF who had had a bilateral transplant for that long. At that time, he had been alive 17 years after his transplant.

When the focus topic for transplants came up this year, immediately I knew whom I wanted to ask to be featured in this column. I still find him to be an inspiration and figured he could be to others as well: people waiting on the transplant list or people like me who have had a transplant but do not see that many people living past a certain amount of time. Paul agreed to be interviewed and we met briefly at the 2012 Transplant Games of America in Grand Rapids, MI. We got to catch up and I got to take his photograph sporting his newly won gold medal! Please welcome our latest star. Spotlight please!

PAUL ALBERT WEARS THE GOLD.

**Name:** Paul Albert
**Age:** 53

**When were you diagnosed with CF?**

Diagnosed at age 3, had a life expectancy of nine years at that time.

**When did you get your lung transplant?**

I received my transplant on February 10, 1993; I was 33 years old at the time.

**Where did you get transplanted?**

I received my transplant at the University of Pittsburgh Medical Center. I go back every few years, but I have a number of specialists I see on a regular basis at Lehigh Valley Hospital, and I get monthly blood work and periodic PFTs. If I have a problem with my lungs, I will return to my doctors at Pittsburgh.

**Did you feel better post-transplant right away?**

It took a while to feel better. I spent the first 111 days post-transplant in the hospital, with over a month in intensive care. I had problems with infection and rejection, sinus surgery, emergency surgery for a lacerated liver, became septic, suffered serum sickness and, finally, kidney failure. When I was discharged I was on dialysis for another 2 ½ months; I was very weak. My PFTs gradually increased and I received physical therapy for five months.

**What were your expectations post-transplant?**

I didn't know what to expect post-transplant. After initial setbacks I just thought about feeling better and going home. I guess after a few years I just expected to keep living without any expectations of how many years that would be.

The transplant obviously exceeded my expectations. I am still alive after 19 years and feeling well. In 1993 it was difficult to find information about lung transplants and life expectancy. My goal was to survive the surgery and then take it from there.

**Would you do it again if need be?**

I can't answer that question now. I would have to consider the people on the list who haven't had an opportunity for their first transplant.

**What was life like after your surgery?**

That was difficult on my body and the port in my chest restricted me. I returned to work full-time on October 1, four months after my discharge. The only time I missed work was when I had to go back to Pittsburgh for a checkup. I became a volunteer with the Gift of Life Donor Program where I learned of the U.S. Transplant Games. That gave me the kick-start I needed to start playing golf again so I could participate in the Games. My first Games were in 1994 in Atlanta. I've remained a volunteer with Gift of Life. I have a desire to help those who remain on the waiting list, waiting for their gift of life.

**How were you feeling pre-transplant?**

I played golf in high school but

then had to give it up as it was too difficult to maintain my weight. As I went through my 20s my lung function was in gradual decline and lung infections were becoming more severe. At least once a year I needed a CF "tune-up". Along the way I fought off a recommendation from my doctor to use supplemental oxygen when sleeping. I finally conceded in my late 20s and it really helped me to sleep better and feel more rested in the morning. After a serious lung infection in May 1992, I came home from the hospital using a Bi-PAP machine when I slept, and on oxygen 24/7. I didn't always use the oxygen in public, but I kept a tank in my car if I needed it. I also came home from the hospital with a list of transplant centers and that started me on my search for a center I was comfortable with in pursuit of a lung transplant.

**What was your daily regimen or health pre-transplant?**

My routine pre-transplant was inhalation treatments three-times-a-day, followed by my parents doing chest percussion on me. That was in addition to pancreatic enzymes, antibiotics, and other medicine that I can't even remember any more. The call from my transplant coordinator came at 11:00pm, while I was receiving chest percussion on Feb. 9, 1993. By the time I came home from work, I was too tired to exercise.

**What is it like now, post-transplant? Do you have any limitations?**

I don't have any restrictions now except for common sense things like avoiding people who are sick, things outside that could harbor mold and fungus, etc. My lung function has consistently been between 70-75%, it has never been higher than that. To me that's 100% because I'm able to do everything that I like. I used to play tennis in addition to golf, but now I'm more afraid of pulling a muscle or hurting myself playing tennis. My lungs aren't holding me back. I try to walk every day to strengthen my bones.

**Tell me about the life-changing pep-talk you received pre-transplant:**

I was having a long stretch in Cardio-Thoracic Intensive Care Unit after transplant when a guy walked in who had CF and a transplant. He asked my parents to leave the room and then he told me to stop feeling sorry for myself, to get off the ventilator, out of bed and feeling better. The guy was Mickey Hart from Buffalo. I didn't see him again until I looked him up on the golf course in Atlanta at my first transplant games. We've been friends ever since. We talk on the phone regularly, enjoy having a drink together at the transplant games and also playing golf. He had two bilateral lung transplants in April 1991 and is doing great.

**How often have you been to the transplant games?**

I've been at 10 transplant games, attending all U.S. Games since 1994. Atlanta 1994, Salt Lake City 1996, Columbus 1998, Disney World 2000 & 2002, Louisville 2004, Minneapolis 2006, Pittsburgh 2008, Madison 2010 and Grand Rapids 2012.

**What do you get out of going?**

At the Games I have a great consciousness of my transplant and how fortunate I am to be doing so well. I enjoy being with so many donor families so they can see the difference their gift made in the lives of others. I enjoy renewing friendships and meeting new people. The competition is fun too! But mostly I credit the transplant games for making the post-transplant "world" so much smaller for us. It gave me the opportunity to meet Mick, and so many others with and without CF.

**What do you compete in when you go?**

At the games I compete in golf, although I did try a relay race in 1998 and badminton in 2000. I've won gold medals in team golf in 1998, 2002 and 2004. In 2012 I won a gold medal in individual golf. That medal was the most satisfying because I didn't play well the first day but came back and played much better on the second day.

**Do you work?**

I graduated from Moravian College with a degree in accounting. For the last 30 years I've been a lead auditor in the Northampton County Controller's Office in Easton, PA. I'm also a Certified Internal Auditor. I've never been on disability, I worked up to the day that I received the call for the transplant.

**Do people at work know about your CF and transplant?**

People at work do know about me having CF and being a transplant recipient. They were very supportive during my transplant and when I came back to work.

**Do you do volunteer work?**

I have been a volunteer with the Gift of Life Donor Program in Philadelphia since 1994. Through them and the Lehigh Valley Coalition for Organ and Tissue Donation, we educate the public about the importance of organ and tissue donation. We have a poster contest, essay contest, fashion show, speaker's bureau and tabletop display for health fairs. In 2004 I joined the board of directors of Gift of Life and remained on the board for six years. The board was composed of transplant surgeons, hospital administrators, donor families and transplant recipients. It allowed me to see how an organ procurement organization (OPO) attempts to maximize the number of organs from each donor, and to hear the concerns from the transplant surgeons. It was a fantastic experience being on the board of the most successful OPO in the world.

*Continued on page 34*

**ALBERT** *continued from page 33*

**What is/are your inspiration(s)?**

From a health standpoint, my inspiration for someone with a transplant is Mickey. He's a great inspiration not just to me, but to a lot of other people too. For someone still battling CF, it's one of my best friends – Lynn Pancoast. In the late '80s she started an adult CF support group for people here in the Lehigh Valley. There are only four of us left. She was a major source of support during my transplant and has the best sense of humor. She keeps getting knocked down with CF and keeps getting back up.

The courage and strength showed by organ and tissue donors, and their families, inspires me. Through their unselfish gift at the most difficult time in a donor family's life, they agree to donate their loved one's organs and/or tissue to save or enhance the lives of strangers.

**What would you tell people about people who are considering a lung transplant?**

I encourage people considering a lung transplant to give it serious consideration. A transplant is the last hope of treatment for people with end-stage lung disease. There are no guarantees with a transplant but, if nothing is done, there's no hope. It's hard work recovering from a transplant, there are new medications to take replacing some you currently take for CF, there may be side effects from the medications, but the upside is limitless. Most people who have suffered with CF and the gradual loss of lung function will have forgotten what it's like to live with good lungs. It's a lot of fun! Go for it! ▲

*Andrea Eisenman is 47 and has CF. She is a Director of USACFA and is the Executive Editor of CF Roundtable and Webmaster. Her contact information is on page 2. Jeanie Hanley is 50 and is a physician who has CF. She is a Director of USACFA and is Vice President. Her contact information is on page 2.*

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

**TILLMAN** *continued from page 27*

**Risk factors for rate of decline in $FEV_1$ in adults with cystic fibrosis.** Michael W. Konstan, Jeffrey S. Wagener, Donald R. VanDevanter, David J. Pasta, Ashley Yegin, Lawrence Rasouliyan, Wayne J. Morgan. Journal of Cystic Fibrosis. Published online 07 May 2012

Risk factors for $FEV_1$ decline over 3–5.5 years for ages 18–24 and ≥25 years were assessed. For the 18-24y group, B. cepacia, pancreatic enzyme use, multidrug-resistant P. aeruginosa, cough, mucoid P. aeruginosa, and female sex predicted greater decline; low baseline $FEV_1$ and sinusitis predicted less decline. For the ≥25y group, only pancreatic enzyme use predicted greater decline; low baseline $FEV_1$ and sinusitis predicted less decline.
http://tinyurl.com/9d68boz

## MYCOBACTERIUM

**The Pharmacokinetics and Pharmacodynamics of Pulmonary Mycobacterium Avium Complex Disease Treatment;** van Ingen J, Egelund EF, Levin A, Totten SE, Boeree MJ, Mouton JW, Aarnoutse RE, Heifets LB, Peloquin CA, Daley CL; American Journal of Respiratory and Critical Care Medicine (Jun 2012)

Currently recommended multidrug treatment regimens for Mycobacterium avium complex (MAC) lung disease yield limited cure rates. This results, in part, from incomplete understanding of the pharmacokinetics and pharmacodynamics of the drugs. Currently recommended regimens for MAC lung disease yield important pharmacologic interactions and low concentrations of key drugs including macrolides. Pharmacodynamic indices for rifampicin, clarithromycin, amikacin and moxifloxacin are seldom met. This may partly explain the poor outcomes of currently recommended treatment regimens. Trials of new drugs and new dosing strategies are needed.
http://tinyurl.com/8ghnqb4

**Risk factors for Mycobacterium abscessus infection in cystic fibrosis patients; a case-control study.** Maarten Verregghen, Harry G. Heijerman, Monique Reijers, Jakko van Ingen, Cornelis K. van der nEt. Journal of Cystic Fibrosis, Volume 11, Issue 4 , Pages 340-343, July 2012

The absence of clear risk factors and the omnipresence of Mycobacterium abscessus (MAB) in the environment suggest that MAB infection in cystic fibrosis patients is a random event. Its symptoms and impact on lung function seem to warrant treatment.
http://tinyurl.com/6s3cqa9

**Mycobacterium avium and Mycobacterium abscessus complex target distinct cystic fibrosis patient subpopulations.** Emilie Catherinot, Anne-Laure Roux, Marie-Anne Vibet, Gil Bellis, Sophie Ravilly, Lydie Lemonnier, Evelyne Le Roux, Claire Bernède-Bauduin, Muriel Le Bourgeois, Jean-Louis Herrmann, Didier Guillemot, Jean-Louis Gaillard. Journal of Cystic Fibrosis. Published online: 02 August 2012

Mycobacterium avium complex affects adult patients with a mild form of CF, whereas Mycobacterium abscessus complex affects younger patients with more severe CF and more frequent

*Continued on page 37*

# CFRI - OH, MY!

*By Laura Tillman*

Having attended the CFRI conference for many years, I have nothing but praise for the quality weekend provided by the conference committee. Great locale, food, atmosphere and speakers is the norm rather than the exception. I'm always impressed by how seamlessly it all seems to go. Yet, I know for a fact that a tremendous amount of time and effort is extended by all of the committee members and staff, who begin work on the next conference almost as soon as this one is over. Additionally, they give up their weekend with family in order to make the conference run like clockwork. Well, okay, admittedly sometimes a few speakers run overtime, but that's just a minor glitch in a weekend chock full of activities.

For those who have never attended the CFRI conference, it begins late Friday afternoon with orientation for the newcomers, followed by a wine reception that includes substantial appetizers accompanied by great music. Afterwards, there is a welcoming session that explains the comprehensive infection control guidelines that are followed throughout the weekend as well as some opening remarks. A "Heroes of Hope" celebration follows two presentations and, finally, it's time to socialize - if one is able to stay awake any longer!

Saturday and Sunday breakfast starts at 7:00 AM!! Yikes! And then the presentation sessions begin after a short welcome. On Saturday morning and afternoon, there are simultaneous sessions that occur; one is for the non-research attendees and the other is for the researchers/medical professionals who wish to hear presentations given by those who have received grant money from CFRI for their research projects. On Saturday afternoon, there is a panel discussion followed by numerous support group sessions for participants to attend if they so wish. This is all followed by another wine reception, an Awards Banquet (and raffle drawing - you should see those raffle baskets!), Memorial Tributes (optional, as they can be very emotional) and, once again, socializing! Whew. Are you worn out yet?

On Sunday, while there still are numerous presentations and an informative "Ask the Experts" Panel Discussion comprised of the weekend's speakers, things wind down. Lunch is a box lunch so that attendees can finish packing and check-out of their hotel rooms on time! And many leave to catch flights back home. It's never easy being the final topic of a conference, so the Panel Discussion is not as well attended as it ought to be. It's a time for anyone who wishes to ask his/her burning questions and to hear what the experts have to say.

> "Attending the CFRI conference is always thought-provoking."

While I have always made an effort to attend the majority of the regular sessions, I found that there were a few this year that had no appeal for me. At my age I had no need to sit through presentations about women with CF having children or men with CF having children. Nor did I feel that a talk on PTSD would be of benefit to me. Instead, I decided to challenge myself by attending the CF Research Presentations.

Oh, my! This was basic research - the stepping stones that lead to further, major research projects that are made public and put in terms that the layman can understand. But at this level and for this audience, there was nothing basic! I did, however, find it interesting to see how differently these sessions operate in comparison to the general sessions. During the "regular" presentations, the speaker is able to convey information without interruption, and then there is an opportunity for the audience to ask questions. Not so, here. There were interruptions for clarification during the lecture as well as numerous questions afterward that almost seemed more detailed in focus than the research itself. Interestingly, the presenter wasn't the only one responding to the queries - many of the audience members answered as well. It was more a give-and-take discussion where the questions and answers seemed to be providing guidance for the researcher. It was overwhelming, both in content and the amount of camaraderie between the researchers.

Attending the CFRI conference is always thought-provoking; additionally it provides an opportunity to see old friends and meet new ones. This year was a bit of an exception - attending some of the research discussions proved to be not just challenging but overwhelming!! The weekend is a full one and can be tiring, but it's well worth the cost, the hassles of travel and the lack of sleep. It's an exciting, fun-filled, information-filled, stimulating and, sometimes, challenging time of learning and friendship. It's well worth attending. ▲

---

*Laura is 64 and has CF. She is a Director of USACFA and is the President. Her contact information is on page 2.*

## CLUB CF ONLINE

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

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

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

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



# People With CF Having Children

*By Maria Fioccola*

The Cystic Fibrosis Research, Inc. (CFRI) 25th Annual conference was held at the Hotel Sofitel in San Francisco Bay, CA on July 27- July 29, 2012. I was honored to attend this year as a newly elected Director of the United States Adult Cystic Fibrosis Association (USACFA). This was the first year I have attended a CFRI conference and I am honored to share my experience with you. Speakers and guests traveled from various locations to attend this year. I traveled from the Chicago-land area.

There were several educational speakers throughout the three-day conference. Since I am a young woman, two speakers stood out to me. Lynn Westphal, M.D. and Paul J. Turek, M.D. spoke about Woman / Men with CF having children. All speakers were willing to answer questions from the audience, before they stepped down from the podium.

Lynn Marie Westphal, M.D., FACOG, has been working full-time at Stanford University since 1998. She is an Associate Professor in the Department of Gynecology and Obstetrics, Director of the Fertility Preservation Program, Director of the Third Party Reproduction Program and the Director of the Reproductive Endocrinology and Infertility (REI) Fellowship. Dr. Westphal caught my interest because I have recently started family planning with my fiancé. She touched base on how pregnancies all are different but not impossible for those who have CF. She reminded those interested in having children to keep in mind that one's current health factors into how a pregnancy may be affected. Dr. Westphal shared with the audience other procedures that can be done to have a biological child, such as IVF (in-vitro fertilization) and surrogacy. She also informed us of how having CF can affect our offspring. Overall, Dr. Westphal's speech gave me inspiration and motivation to keep hope in my family planning.

Paul J. Turek, M.D. is a Director of the The Turek Clinic, a men's health clinic in San Francisco. His presentation was titled "Men with CF are Having Children." He educated the audience on how male fertility is an easier problem to remedy than female fertility. He taught us therapy methods and procedures that can be done for men to have biological children. He reminded the audience that a man's overall health is important as well. Things that don't factor into having children included age, anatomy and CF mutation. Important factors are your partner's age and health. Dr. Turek's speech was educational to me because he touched base on how men who are carriers can also suffer from similar infertility issues. I am thankful I listened to his speech because I can use this information for myself and others who are family planning.

For me, the Cystic Fibrosis Research, Inc. 25th Annual conference was a success. I left feeling more knowledgeable, inspired and motivated to keep involved in the cystic fibrosis community. I look forward to attending next year. The speakers were just one great part of the conference. I feel honored to have met new people whom I now can call my friends. ▲

---

*Maria is 27 and has CF. She is a Director of USACFA. Her contact information is on page 2.*

# Nourishment for the Soul

*By Paul Feld*

The 2012 CFRI Retreat was aptly named this year. I can't think of another gathering I have attended this year that so invigorated my soul. From July 29th through August 5th, on the grounds of the serene Vallombrosa Center in Menlo Park, CA, spirits were lifted for all involved. This year, about 30 young adults experienced at least part of the retreat activities, and even a few older adults, over 40, attended and shared their wisdom as well. As always, another 10 folks or so provided support throughout the retreat. They were led by Jessica Martens, who has done a wonderful job of managing retreat activities the last couple of years.

This year, we had about a half dozen new faces join us. Most were very young, either late teens or early twenties, although they displayed an awesome sense of maturity for people so new to the group. They spoke honestly, freely, and with a passion for life which I have not seen in quite a while. They knew that, in a way, we all have this terminal illness. They wanted to know how to best live life now, how it's OK to get angry where appropriate, and yet still have the hope that they could possibly live until retirement, and should plan to do so. At 55, I was the senior member of the group this year, but it was remarkably humbling to see folks continue to attend from 2004, the year I first started coming to retreat. Those 'kids' were in their 20s and 30s then, and most have moved on to the next decade. It was notable that about five retreat members were 40 or older, and I pray they all get to see '55', as I have.

About half the retreat-ants have had lung transplants, and we discussed at length one evening how the transplants and non-transplants can learn from one another. As a transplant patient myself, you quickly forget how hellish life was with your original lungs when you have a new pair working so well. At the same time, transplanted patients can provide a lot of guidance to those who have not gone through the process yet but, hopefully will have that opportunity when their current lungs can no longer sustain them.

So, what did we do? Personally, I was only able to stay at retreat for the first five days of the seven-day-plan, yet it was full of activities. In those first five days we had five rap sessions, all of which were at least 90 minutes in length. I find these to be the highlight of retreat, where all of us with CF can express our thoughts on a variety of topics. It's important to note that in rap session 1, we define our topics for the week and focus on those for discussion. We always seem to have more topics than time permits, but I get the impression that few walk away from retreat with unresolved issues.

For exercise we had yoga, zumba, and u-jam fitness in those first five days. Few got away unscathed. For entertainment, we had an improv night on Monday and jeopardy/hunger games on Thursday evening – what a blast! For education, the girls had a reproductive health discussion, followed the next day by a career workshop discussion for all, and finally an infectious disease talk provided by a Stanford infectious disease physician, with plenty of time for Q & A. The day I left, there was also going to be a Palliative Care discussion. Finally, we had our memorial evening on Tuesday. This is where we remember our friends, families, and donors who have rounded our lives to what they look like today, and we are all better because of our experiences with them. From the heart, lots of tears, lots of love.

I wish I could have stayed for the entire week. I missed 'cupcake wars' and 'talent night', where I usually laugh as hard as I do all year. Also, after departing, the group put a video together which is now on YouTube. To view, use the link below. All you will find is fun, and smiling faces. ▲

http://www.youtube.com/watch?v=1XkkXKhv8Ls.

---

*Paul is 55 and has CF. He is a Director of USACFA. His contact information is on page 2.*

---

**TILLMAN** *continued from page 34*

intravenous antimicrobial treatment.
http://tinyurl.com/9n4zehk

---

**High-resolution CT of nontuberculous mycobacterium infection in adult CF patients: diagnostic accuracy.** Sinead McEvoy, Lisa Lavelle, Aoife Kilcoyne, Colin McCarthy, Pim A. deJong, Martine Loeve, Harm A. W. M. Tiddens, Edward McKone, Charles G. Gallagher and Jonathan D. Dodd. EUROPEAN RADIOLOGY2012

Key points found in this study include: 1) Lung function declines rapidly in cystic fibrosis patients with nontuberculous mycobacterium infection. 2) High-resolution computed tomography can help identify nontuberculous mycobacterium in CF patients. 3) Extensive collapse/consolidation and tree-in-bud/centrilobular nodules are predictive of NTM infection. 4) Multiple bronchopulmonary segments showing tree-in-bud/centrilobular nodules strongly suggest nontuberculous mycobacterium infection.

*Continued on page 38*

http://tinyurl.com/bm6hsod

## BACTERIA

**A heat-stable cytotoxic factor produced by Achromobacter xylosoxidans isolated from Brazilian patients with CF is associated with in vitro increased proinflammatory cytokines.** Rebeca P. Mantovani, Carlos E. Levy, Tomomasa Yano. Journal of Cystic Fibrosis. Volume 11, Issue 4 , Pages 305-311, July 2012

The cytotoxic factor produced by A. xylosoxidans may represent an important virulence factor, which when associated with CF chronic lung inflammation, may cause tissue damage and decline of lung function.
http://tinyurl.com/7a6nlbg

**Multiple antibiotic-resistant Pseudomonas aeruginosa and lung function decline in patients with cystic fibrosis.** Clement L. Ren, Michael W. Konstan, Ashley Yegin, Lawrence Rasouliyan, Benjamin Trzaskoma, Wayne J. Morgan, Warren Regelmann, for The Scientific Advisory Group, Investigators, and Coordinators of the Epidemiologic Study of Cystic Fibrosis. Journal of Cystic Fibrosis. Volume 11, Issue 4, Pages 293-299, July 2012

Newly detected multiple antibiotic–resistant Pseudomonas aeruginosa (MARPA) was not associated with a significant change in the rate of forced expiratory volume in 1second decline. These results suggest that MARPA is more likely to be a marker of more severe disease and more intensive therapy, and less likely to be contributing independently to more rapid lung function decline.
http://tinyurl.com/79sl46j

## TREATMENTS

**Ivacaftor in Subjects With Cystic Fibrosis Who Are Homozygous for the F508del-CFTR Mutation.** Patrick A. Flume, MD, FCCP; Theodore G. Liou, MD, FCCP; Drucy S. Borowitz, MD; Haihong Li, PhD; Karl Yen, MD; Claudia L. Ordoñez, MD; David E. Geller, MD. CHEST.2012;142(3):718-724

The objectives of this study were to evaluate the safety of ivacaftor in a larger population and for a longer time period than tested previously and to assess the efficacy of ivacaftor in subjects with CF who are homozygous for F508del-CFTR. The results expand the safety information for ivacaftor and support its continued evaluation. Lack of a clinical effect suggests that a cystic fibrosis transmembrane conductance regulator (CFTR) potentiator alone is not an effective therapeutic approach for patients who have cystic fibrosis (CF) and are homozygous for F508del–CFTR.
http://tinyurl.com/9z8pyo4

**Optimization of anti-pseudomonal antibiotics for cystic fibrosis pulmonary exacerbations: III. fluoroquinolones.** Chris Stockmann MSc, Catherine M.T. Sherwin PhD, Jeffery T. Zobell PharmD, David C. Young PharmD, C. Dustin Waters PharmD, BCPS, Michael G. Spigarelli MD, PhD, Krow Ampofo MD. Pediatric Pulmonology. Article first published online: 4 SEP 2012

A recent pharmacodynamic (PD) modeling study shows that the literature, U.S. Food and Drug Administration approved, and Cystic Fibrosis Foundation guideline dosing regimens may be suboptimal for the treatment of P. aeruginosa in acute pulmonary exacerbations (APE). Further study is warranted to determine if higher doses of ciprofloxacin are needed. Limited pharmacokinetic and efficacy studies involving levofloxacin exist in adult patients with CF. No pediatric data exists for levofloxacin in CF patients. Further study is needed to determine the tolerability and efficacy of levofloxacin in APE. At this time, the routine use of levofloxacin in the treatment of APE in pediatric and adult patients cannot be recommended.
http://tinyurl.com/8l5ku5w

**A network meta-analysis of the efficacy of inhaled antibiotics for chronic Pseudomonas infections in cystic fibrosis.** Kavi J. Littlewoo, Kyoko Higashi, Jeroen P. Jansen, Gorana Capkun-Niggli, Maria-Magdalena Balp, Gerd Doering, Harm A.W.M. Tiddens, Gerhild Angyalosi. Journal of Cystic Fibrosis. Published online 21 June 2012

Various inhaled antibiotics are currently used for treating chronic Pseudomonas aeruginosa lung infection in cystic fibrosis (CF) patients; however their relative effectiveness is unclear. The efficacy of inhaled antibiotics tobramycin (TIP, TIS-T, TIS-B), colistimethate sodium (colistin) and aztreonam lysine for inhalation (AZLI) based on data from randomised controlled trials were compared. The authors conclude that all studied antibiotics have comparable efficacies for the treatment of chronic P. aeruginosa

## *In Memory*

**Melissa Cokelet Brown**, 36
Hazlet, NJ
January 24, 2012

**Marjorie R. Winokur**, 59
New Hyde Park, NY
August 17, 2012.

*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

## CF ROUNDTABLE SUBSCRIPTION FORM (Please Print Clearly)

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

**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 $15 for individuals, $25 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 $4.00 per copy requested. . . . . $ _____
- Please send gift subscriptions to the names and addresses I have listed
  on a separate sheet of paper. I have enclosed $15 per subscription ordered. . . . . $ _____

**TOTAL** . . . . . $ _____

Please do not write in this space

AU 12

**Make checks payable to USACFA and mail with this completed form to:** USACFA, P.O. Box 151024, Alexandria, VA 22315-1024
Everyone must complete a subscription form annually to be included on our mailing list. Please check mailing label for renewal date.

**OR**

**You can also subscribe online!** Go to www.cfroundtable.com By subscribing online you have the ability to download a PDF of the latest newsletter, receive the mailed verision or you can receive both. The online version will be available two weeks prior to the mailed version.

## HOW TO RENEW YOUR SUBSCRIPTION

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 2013.) If there is no date or it says (TIME TO RENEW), your subscription is due for renewal.

KATHY RUSSELL 5/13
4646 NE DIVISION STREET
GRESHAM, OR 97030-4628

Please be sure to complete and return a 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 $3.73 per returned copy.)

**Thank you for helping us with this.**

**TILLMAN** *continued from page 38*

lung infection in CF.
http://tinyurl.com/9ow8nn2

**Azithromycin maintenance therapy in patients with cystic fibrosis: A dose advice based on a review of pharmacokinetics, efficacy, and side effects;** Wilms EB, Touw DJ, Heijerman HG, van der Ent CK; Pediatric Pulmonology 47 (7), 658-65 (Jul 2012)

It was concluded that a dose level of 22-30 mg/kg/week is the lowest dose level with proven efficacy. Due to the extended half-life in patients with CF, the weekly dose of azithromycin can be divided in one to seven dosing moments, depending on patient preference and gastro-intestinal tolerance. No important side effects or interactions with other CF-related drugs have been documented so far. ▲
http://tinyurl.com/7ltkrmx

*Laura Tillman is 64 and has CF. She is a Director of USACFA and is the President. Her contact information is on page 2.*

## 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 **(248) 349-4553**. You may email us at **cfroundtable@usacfa.org**
- Send your questions of a general nature regarding legal issues that relate to CF to our legal advisor: **Beth Sufian, Esq., 712 Main, Suite 2130, Houston, Texas 77005. Email: cflegal@cff.org**.
- You may subscribe at cfroundtable@usacfa.org

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

## IMPORTANT RESOURCES

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

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

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

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

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