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

How You Can Help Guard Against Errors

Experts say that you, as a patient, have one of the most important roles to play in protecting yourself from medical errors.

Here are some tips for patients, compiled from the Joint Commission on Accreditation of Healthcare Organizations, the U.S. government's Agency for Healthcare Research and Quality, and interviews with experts.

Active Participation

- Take part in every decision about your health care.
- Ask questions, and speak up about anything that you don't understand or that causes you concern.
- If you are not prepared to ask questions on your own behalf — because of personality, illness or other reasons — ask a family member or friend to fill this role for you.

Medications

- Keep a list of everything you take. Make sure you know the dosages and the purpose of the medicines.
- Read medicine labels, including warnings. Learn what side effects to watch out for, whether the medicine has dangerous interactions with other drugs, and whether you should avoid certain activities — such as drinking alcohol or spending time in the sun — while you are taking it. If you have concerns or questions, ask your pharmacist or your doctor.
- Tell all of your doctors and your pharmacist about every drug you are taking, and any allergies. This includes prescription drugs, over-the-counter drugs, vitamins, supplements and herbal products. Bring your medicines to your doctor appointments.
- Make sure the medicine you receive is what the doctor actually prescribed. If it looks different from what you expected, ask the pharmacist about it.

Test Results

- Make sure you get the results of every test, and understand what they mean.
- If you do not hear about test results, never assume that everything is all right. Call your doctor's office and ask.

Hospital Stays And Surgery

- Whenever possible, choose a hospital where many patients receive the same procedure that you need. There is no independent source of data in most states. Ask your doctor or hospital staff for the numbers.
- Ask the people who care for you if they have washed their hands. This may make them wash more often.
- If you are having surgery, make sure that you, your doctor and your surgeon all agree on what will be done during the operation.
- Ask about how long the procedure will take, the potential risks and complications, and what your recovery period may be like.
- Make sure that everyone who takes care of you in the hospital knows all important health information

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INSIDE THIS ISSUE

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

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A WORD FROM THE PRESIDENT...

I just have to start this column with heartfelt congratulations to **Andrea Eisenman,** our Executive Editor and Webmaster. Andrea was married recently, and I'm sure the entire Board of USACFA would join me with a wish of many wonderful years together with her husband **Stephen.** And speaking of husband, **Steven,** slightly belated congratulations also go out to **Cynthia Dunafon,** our Vice-president. She was married this past May. I think it speaks volumes when we have these adult CF women taking this leap in their 40s! Look how far we've come!

I rarely write about our *Maibox* column. Very few things fill the USACFA board with pride more than reading feedback from our subscribers and readers. We continue to encourage and solicit feedback to our newsletter to make it the best it can be, even if it's as simple as stating that a particular article really touched you. This kind of feedback simply reminds us that our volunteer efforts are worth every second we put into it.

Our FOCUS topic for this issue is "Organ Transplants", and it's usually a hot topic. Very few people are on the fence about it, being very much in favor or very much opposed to it. But the fact is, for most CF adults, there will come a time where this becomes your only good option to extend your life. We hope our four articles on this topic will open your eyes a bit wider to the transplant experience.

The 21st Annual CFRI Educational Conference took place, once again, in Redwood City, California, in early August. Four USACFA Directors were able to attend and provide conference feedback. I urge you to read all the educational material from **Rich DeNagel, Laura Tillman, Cynthia Dunafon,** and **Maggie Sheehan.**

In *Voices from the Roundtable*, **Kurt Robinson** and **Joy Heinsohn** share their experiences relating to 'home care or hospital' and 'running', respectively. I enjoyed reading both of them as I have lived both experiences myself. **Debbie Ajini** shares Part 2 of her experience at UPMC and getting her pre-transplant workup and results. In his *Unplugged* column, **Rich DeNagel** is interviewed on the other side of the mike, and we all get to know him a little better. In her *Ask the Attorney* column, **Beth Sufian** discusses the PASS plan and inhaled drugs covered under Medicare Parts B & D. **Dr. Julie Desch** defines 'compliance', from her perspective, in her *Wellness* column; and I agree with her last two sentences - 100%. **Isabel Stenzel Byrnes** talks about her thrill to be a part of a national political convention and how it lifted her spirit, in *Spirit Medicine*.

Finally, enjoy the photos and descriptions brought to you by *Pammie Post*, and reflect on how fortunate we all are to enjoy them today.

Peace,

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

MILESTONES

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

ANNIVERSARIES

Birthday

Debbie Ajini
Shelby Township, MI
38 on August 3, 2008

Cara Brahm
Lebanon, KY
32 on September 10, 2008

Beth Sufian
Houston, TX
43 on August 13, 2008

Janet Reed
Woodsfield, OH
46 on August 19, 2008

Wedding

Donovan & Jacelynn Couture
Colchester, VT
20 years on July 23, 2008

Ann & Jon Williman
Middletown, OH
34 years on August 31, 2008

Valerie Vandervort & Rick Boyer
Claremore, OK
17 years on June 14, 2008

Transplant

Donovan Couture, 40
Colchester, VT
Bilateral lung
10 years on September 4, 2008

Janet Reed, 45
Woodsfield, OH
Bilateral lung
6 years on August 10, 2008

Valerie Vandervort, 36
Claremore, OK
Bilateral lung
7 years on October 4, 2008

NEW BEGINNINGS

Wedding

Andrea Eisenman & Stephen Downey
New York, NY
Married on September 13, 2008

LOOKING AHEAD

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

Autumn (current) 2008: Organ Transplants

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

Spring (May) 2009: Making Career Choices with CF. (Submissions due March 15, 2009) Choosing the right career can make a tremendous difference in one's life. Do you have any insights for our readers about how to make the right decision? Can you tell us of any pitfalls to avoid?

Summer (August) 2009: Becoming A Parent With CF. (Submissions due June 15, 2009)

ASK THE ATTORNEY

Questions from Readers

By Beth Sufian, Esq.

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

1. Does Social Security have any programs that allow Supplemental Security Income (SSI) recipients to engage in work activity while either keeping Medicaid benefits or keeping the SSI benefit and Medicaid coverage?

BETH SUFIAN

Social Security has two basic programs that allow SSI recipients to work and continue receiving either their monthly cash benefit check and Medicaid, or allows them to receive Medicaid. The first program is called a Plan for Achieving Self Sufficiency (PASS). A PASS plan allows SSI recipients to set aside money or other things of value to help the SSI recipient reach a career goal. For example, an individual could set aside money to start a business or to go to school to obtain training for a specific job. The career goal must be a career that will produce sufficient earnings to reduce dependency on SSI payments. A PASS plan is meant to assist an SSI recipient in acquiring items, services or training needed to compete with those not receiving benefits in a professional, business or trade environment. Typically, a PASS plan can last 36 months.

A person who would not otherwise be eligible for SSI benefits can set aside income and resources in a PASS plan to become eligible for SSI benefits. This is VERY important. For example, if a person with CF meets the SSI medical requirements but has $4,000, he will not be eligible for SSI benefits because he is over the income guidelines. Under the SSI income guidelines, a single person can have only $2,000 in assets. However, if the person drafts a PASS plan and the plan is approved by SSA, the person can put his assets in the PASS plan and then be eligible for benefits.

A PASS plan must:

1. Be in writing.
2. Be approved by SSA.
3. Have a specific work goal which the person can probably reach.
4. Indicate how long it will take the person to reach the work goal.
5. Indicate what income and resources the person will set aside and how it will be spent.
6. Explain how the person will keep income and resources separate from other money.
7. Describe any goods and services the person will need to reach the goal and explain why he needs them.

During the period that the PASS plan is in effect the SSI recipient can work and save money made from work earnings in a savings account. The funds will not count toward the SSI asset and income limits. In addition, the SSI recipient can keep Medicaid benefits during the time the PASS plan is in effect. The PASS plan must be discussed with a representative from Social Security and must be memorialized in writing. It must describe what the money, the SSI recipient is making, is being saved for. For example, if the SSI recipient is saving money to pay for college tuition in the future, that must be noted in the PASS plan. If the SSI recipient is saving money to open up a small business, the type of small business and plans for the business must be set out in the PASS plan.

The second type of SSA work program is known as Section 1619(b). Section 1619(b) of the Social Security Act provides some protection for these beneficiaries. To qualify for continuing Medicaid coverage, **a person who works and makes over the SSI income amount must:**

1. Have been eligible for an SSI cash payment for at least one month;
2. Still meet the medical require-

"A PASS plan allows SSI recipients to set aside money or other things of value to help the SSI recipient reach a career goal."

ments; and
3. Still meet all other non-disability SSI requirements; and
4. Need Medicaid benefits to continue to work; and
5. Have gross earnings that are insufficient to replace SSI, Medicaid and publicly funded attendant care services.

This means that SSI beneficiaries who have earnings that are too high for an SSI cash payment may be eligible to keep their Medicaid benefit, if they meet the above requirements. SSA uses a threshold (cut-off) dollar amount to measure whether a person's earnings are high enough to replace his/her SSI and Medicaid benefits. This threshold is based on the amount of earnings which would cause SSI cash payments to stop in the person's State; and average Medicaid expenses in that State.

Each state has a different threshold amount. To find out your state's cut off amount go to http://www.ssa.gov and put Section 1619(b) in the "search" area box. The screen will indicate each state and the threshold amount that a person can make and still keep Medicaid. Section 1619(b) helps the person with CF who is on SSI and can work part time but will not be eligible for health insurance benefits at work, if he is working part time (note: most employers do not provide health insurance benefits to employees who work part time). If the individual is able to work part time and will make more money working part time than he will receive in SSI benefits, Section 1619(b) will allow the individual to work part time and keep Medicaid.

The person will lose his monthly SSI cash benefit. If the person becomes unable to work he should be able to resume SSI payments without reapplying for benefits. However, Social Security will usually check to make sure the person still meets the SSI medical requirements. There are other limited ways to work and receive partial SSI benefits. Before going back to work, an SSI recipient should make sure he understands the SSI income guidelines in the state.

There are different rules concerning work activity for people who receive Social Security Disability Income (SSDI) benefits. If a person works for an employer in 2008, the person can make approximately $940 a month from part time work. However, the number is lower if a person is self-employed. A person who is self-employed should check with Social Security to determine the income cut-off amount the person can make from work activity. Those who have both SSI and SSDI should make sure to understand how each program's work rules will interact.

2. Are inhaled drugs used to treat CF covered under Medicare Part B or Part D?

Inhaled drugs used to treat cystic fibrosis are covered by Medicare under Medicare Part B. Part B covers any FDA approved drugs that are used with durable medical equipment. Inhaled drugs used to treat CF are used with nebulizers and nebulizers are durable medical equipment, so the drugs are covered by Part B. Examples of such drugs would be Pulmozyme® and TOBI®. Colistin, which is used off label for people with CF and is not FDA approved for inhaled use, is not covered by Part B and so should be covered by Part D.

There are approximately only 25 drugs covered by Part B, so most pharmacies and physicians have no idea that Part B covers a limited number of drugs. Some pharmacies do not know how to file the paperwork on a Part B medication claim. If you are having trouble finding a pharmacy, you can contact CF Services Pharmacy at 1-800-541-4959. CF Services is knowledgeable on the filing of Part B claims. ▲

Beth is 42 and has CF. She is a Director of USACFA. Her contact information is on page 2. You may send her questions of a legal nature that are CF-related.

Help Wanted: Web Site

USACFA is looking for a volunteer to help with updates to our Web site – www.usacfa.org – during 2009. We are looking for someone who is knowledgeable in Adobe DreamWeaver, Adobe Photoshop and Adobe Illustrator. Our current Web site designer, Andrea Eisenman, does an amazing job with our newsletter and Web site, but we would like to get some involvement from the CF community. For our initial updates during the first quarter of 2009, there would be 10-12 hours of work. Then assisting with updates on a quarterly basis would run 1-2 hours. If you are interested, please contact Andrea at aeisenman@usacfa.org and she will be able to work out the details with you.

Thank you for your continued support of all we do; we appreciate ALL of our volunteers very much!

SPIRIT MEDICINE

The Patriotic Spirit with CF

By Isabel Stenzel Byrnes

During the last few months, Americans have all been inundated with patriotic stories and promises by presidential candidates. At the end of the summer, thanks to my husband's involvement, I was privileged to attend a national convention. This was the first time in my life I've been able to be well enough to attend such a large-scale political event. I saw firsthand the excitement and energy of our political process. In this article, I'd like to share how witnessing this political event affected my spirit: *my political spirit*. I left the convention with admiration, gratitude, and a call to action.

At the convention, I looked upon the crowds like an outsider — and it wasn't just because I wore a mask to protect myself from germs! I marveled at the tens of thousands of zealous Americans who screamed and cheered in support of their candidate and their causes. Like me, they all want to make the world a better place while they are living in it, and they chose politics as their passion, just as my CF involvement has been mine. It really doesn't matter what party one belongs to; I was just moved by these people who genuinely care about their country and the world. I saw people dressed up in red, white and blue, carrying signs and wearing T-shirts and pins with their favorite candidate — all seeking and finding a sense of belonging in their political community - just as I've found mine in the CF community.

To be honest, I envied that these political-types had the luxury to participate in the political process. For most of my life, I cared about American society, but just had too much on my plate to put my care into action. Every day I focused on my health needs, my treatments, my health insurance battles, and what I needed to do next in my life to function. I realized at the convention that CF can be very self-absorbing; it inadvertently created apathy in me because I was just trying to stay alive. Now, with stable health post-transplant, I have energy to engage in this new political scene. There is so much to know about how America operates and much to understand about the problems that need fixing. At the convention, I felt mobilized to educate myself about how the candidates stand on the issues, especially health care and disability rights that would affect my friends with CF and me.

For some, political involvement is a spiritual calling. At the beginning and end of the convention, spiritual leaders recited benedictions stating reminders like, "It is our sacred responsibility to advocate for all the people, most especially the least, the last, and the lost," and also, "we pray that God will guide us in our decision making as we renew our commitment to protect… those in the shadows of life that scripture calls upon us to serve: the poor, the sick, the disabled, the stranger, the immigrants.". These prayers were a moving charge for people to remember why they are caught up in the excitement of the convention circus; caring for those less fortunate is a spiritual act. The convention awakened inside of me the awareness that to be part of a cause that is so much greater than oneself is indeed healing in its own way. My life with CF happens in a larger context of our society as a whole. As I have been the recipient of much advocacy I, too,

ISA STENZEL BYRNES

could advocate for those who need it. The feeling that I have something to contribute is good for my spirit.

Many of the speeches sounded the same after a while, with the common theme of national pride, unity and a candid report of the many social, economic and political problems of today. The candidates and their supporters spoke of the American Dream: the unique promise in this country that everyone has opportunity to reach their "God-given potential". Once I dismissed my cynicism, I could reflect on how much our country has offered people living with cystic fibrosis. Unlike in many other countries, the label of CF alone does not prevent us from pursuing our dreams; like getting into college, marrying the person we love, becoming parents or advancing our careers and passions. My patriotism grew as I thought about how America was the nation that discovered this disease back in 1938 and the gene in 1989. Ours is the country where the chest vest, Pulmozyme®, and countless other treatments for CF have been discovered. Our Food and Drug Administration, though plagued with problems, approved Pulmozyme in record time back in 1993. Science in the United States led to the first organ transplants, and our government supports legislation that makes organ donation possible.

There are so many laws that our country has created to promote our health. Thanks to our nation's charitable donations tax laws, Americans donate to non-profits more than any other country, so that organizations like the Cystic Fibrosis Foundation and Cystic Fibrosis Research, Inc., can do their great work. Because of these non-profits, the life expectancy for CF people has climbed to 37 years in just a few decades. Though other countries do surpass us, we Americans have reason to be grateful for thriving and surviving without socialized medicine. In 2007, I heard from an Argentinean nurse that the average life expectancy for CF kids in her country is 12 years. Similar statistics apply to CF people in Central America or Eastern Europe. It is just pure luck that we were born here in America with CF.

As people with CF, our country has offered us protection through laws like the Americans with Disabilities Act and Family Medical Leave Act. The Orphan Drug Act that promotes research for rare diseases like CF has also played a role in prolonging our life expectancy. While far from perfect, people with CF have the opportunity to acquire and keep health insurance through state children's health insurance programs, Medicaid, Medicare, and even COBRA and the Health Insurance Portability Accountability Act. Women with CF with advanced disease or post-transplant who become pregnant do not have to risk their survival because our country protects their right of choice. The list of laws that benefit people with CF goes on and on.

> *"At the convention, I felt mobilized to educate myself about how the candidates stand on the issues, especially health care and disability rights that would affect my friends with CF and me."*

The gratitude I felt for what this country has offered people with CF was coupled with thoughts of what I could offer my country. After dozens of speeches, I realized that what makes a good cause, and a good candidate, is a good personal story. And I thought about how all of us have a compelling story to share with our lawmakers and decision makers to give them a glimpse into our world with cystic fibrosis. I recall hearing Molly, a teenager with CF, speak in front of our state legislature to share her story of a late diagnosis and a plea for approval of the CF newborn screening law. I appreciated the warm words of understanding from lawmakers, when I spoke for the Disability Caucus at our state convention earlier this year. Sharing my story with CF has been like narrative therapy for me; I always feel more confident and validated afterwards. Most lawmakers have no idea what CF is or what we go through unless we share our stories with them. I am realistic that these politicians cannot fix all of our problems, or find a cure for CF soon, but they can be moved to support laws to help us.

There are few patient populations that have such compelling reasons for health care reform than the CF community. At the 2008 CFRI Conference, Dr. Richard Simon said our average annual cost of *routine* CF medical care is $75,000! Though I've been lucky with good health insurance, I know CF families who had to sell their home to pay for medical bills; or one friend who lost health insurance for six months and declined so precipitously that he ended up needing a transplant — and qualifying for Medicaid. Our advocates, like the CFF's Congressional Caucus, can do only so much. The rest is up to us. The convention left me with a desire to take action. The convention energy inspired hope and optimism in the

Continued on page 27

WELLNESS

Are You Compliant?

By Julie Desch, MD

I can't really speak to the focus of this issue of *CF Roundtable*, transplantation, other than to say that I am continually amazed by the courage and sense of gratitude that emanates from everyone I meet who has undergone the procedure. I hope only that when/if it becomes necessary for me, I will handle it as well. Instead, I am going to take this opportunity to vent on one of my pet subjects: compliance.

I don't know about you, but when I hear people who don't have CF talk about the difficulty of "compliance" in people with CF, I become a touch irritable. I know that doctors mean well, that parents mean well, and that psychologists mean well as they look for ways to "increase compliance" in those of us with CF.

As a doctor myself, I understand the frustration your doctors feel when their suggestions are not taken. It drives them crazy. They know from years of training and practice, and from reading current research papers, exactly what their patient (you) should do to optimize health. They have this valuable information and they think that you should take this information and ACT!

Indeed, this is probably a mere fraction of the frustration a parent must feel when their child doesn't do his/her prescribed treatments or take prescribed meds. Then, not only do they think they know better (and they do), but this is their *child* whom they love and want more than anything to be healthy. But the doctor and the parent do not live in the body that needs these treatments. They look in from the outside with their "expert hat" on, *tell us* what to do, and expect us to do it. And when we don't do it, we are "noncompliant." Boy, do I hate that word. It adds to the problem! It labels the patient/child as someone who will not change…as someone who is difficult, defiant, a pain in the a**! When, really, the patient/child is simply not yet ready to change, and could use some assistance with the change process.

What does it take for a person who is *not* doing something (taking a medicine, doing an aerosol treatment, doing CPT or the VEST®, taking enough enzymes, eating enough or eating better, exercising…you name it) to start doing something? I'll give you a clue: it is NOT information or a prescription from the doctor/parent alone. That is a start – a good start! I would love it if every CF doctor actually prescribed exercise, for example!

> *"When I hear people who don't have CF talk about the difficulty of "compliance" in people with CF, I become a touch irritable."*

JULIE DESCH, MD

What is needed beyond the prescription, though, is "behavior change". Behavior change is a process that has been studied extensively. As a wellness coach, I have learned all about behavior change. In fact, I recently wrote an entire chapter entitled "How We Change" in a text for personal trainers who are certifying with the American College of Sports Medicine.

Behavioral science tells us that successful behavior change occurs in distinct and predictable stages. You can't skip stages and expect lasting change. Additionally, there are processes and strategies that are distinctly beneficial to use in some stages and not others. In fact, using a strategy that is mismatched to a person's stage of readiness to change can be, frankly, detrimental.

I don't intend to go into a long recitation of the stages of readiness to change and processes for each stage. What I do want to stress is that getting someone to "do what you say" does not work. In my opinion, <u>now</u> is time to apply proven behavioral science techniques to the adult CF population, and assist them in finding their own reasons to change.

How do we do that? First, if you have been branded as "noncompliant", forget that! People are not either "compliant" or "noncompliant". It is not that simple! When I work with someone who has been <u>told</u> by their doctor to start exercising, do you think they immediately jump on a treadmill? Of course not. Are they being "noncompliant"? Well, sort of; but that is not the point! The point is, you don't just start exercising one day any-

more than you actually achieve an ill-planned New Year's resolution.

One of the reasons that coaching works is that an effective coach helps their clients first develop the vision of where they want to go (what changes do they want to make?) and then find their own intrinsic motivators: why they want to change…what will be better…how will their life improve? Intrinsic means it comes from the clients themselves, as opposed to extrinsic, which is a change you want to make to please someone else or to achieve some objective measurement. An intrinsic motivator is a personal thing, a feeling, a sense of accomplishment, self-confidence, etc. An intrinsic motivator will always be there – it won't go away when the goal is reached. For example, you may have a goal imposed on you (extrinsic) by your doctor to do your hypertonic saline (HTS) twice-a-day. You do it, but only so that you are not labeled a "noncompliant" patient. Then, your doctor stops asking and you slack off, and you realize that you feel much worse. You cough more. It's harder to clear sputum. You are run down. Suddenly, you have an intrinsic motivator – you know that you feel better on HTS. It doesn't matter what your doctor tells you about the benefits anymore, you do it because you know that you will feel better, and you want to feel good.

The "noncompliant" patient has not yet discovered compelling intrinsic motivators to do what it takes to optimize health. This is what needs to be addressed; not their stubbornness, or laziness, or general pain-in-the-___ness. We do what we *want* to do. We need to discover why we *want* to be as healthy as we can be. "Compliance" will follow. ▲

Julie, who turned 48 on November 5, 2008, is a physician who has CF. You may direct your questions regarding CF-related health issues to her at: jdesch@usacfa.org.

USACFA Director Receives Award

At the 2008 CFRI Educational Conference, Andrea Eisenman, who is USACFA's Executive Editor and Webmaster, was named the recipient of the annual Dave Stuckert Memorial Volunteer of the Year award. This award is given in memory and honor of a man who was the model volunteer. Many well-known people have received this award and they are honored to have Andrea join them.

Andrea is 43 years of age. She has been active in the CF community for most of her life. She mentors others who have CF and offers assistance to those who are dealing with CF as well as transplants.

Andrea had a bilateral lung transplant in April 2000. In early 2001, when she felt reasonably recovered from her surgery, she became a Director of USACFA. She brought a lot of talent to the group.

Andrea was a graphic designer by profession, and she started designing and doing the layout of *CF Roundtable* in early 2002. In mid-2004, Andrea became the Executive Editor/Webmaster for USACFA. She works very hard to put out a quality publication. She doesn't *just* do the layout and design, she also writes articles for the newsletter.

Andrea is an active advocate and spokesperson for the New York Organ Donor Network, an organ procurement organization. She speaks to CF families at education events and is open about sharing her story. She is an active member of Team Liberty, for the United States Transplant Games. She is a role model for taking care of herself and exercises regularly. She is a medal winner at the Transplant Games each year that she participates.

ANDREA EISENMAN

Andrea is extremely hard working. She lives a balanced life and spends her time helping others and tuning her body to provide her with the best health possible. She is humble and full of care for others. She demonstrates that we all can live a good, long life by pacing ourselves, loving others deeply, doing what we love, and living outside of the box.

We at USACFA are very proud of Andrea and include our congratulations with those of CFRI, Inc. ▲

Webcasts Sponsored by the CFF

Check in regularly at www.cff.org for information about Virtual CF Education Day Webcasts, sponsored by the CF Foundation. The January Webcast will feature experts discussing cystic fibrosis fertility and pregnancy issues. Check out the Website for more information: www.cff.org.

SPEEDING PAST 50...

The Saga of the Polka Dot Shoes

By Kathy Russell

The hurricanes seem to be easing and autumn is firmly ensconced. Here, the autumn crocuses are resplendent in their lovely, lavender color. They always cheer me. The tomatoes are canned and the sweet pickle relish and chili sauce are put up, so it is time to start thinking of cooler-weather activities. That means it is time for hot cocoa, hot tea, hot cider and good foods from the crock pot. I love it. I look forward to the warm treats of autumn and I hope you have a pleasant autumn, too.

Today, I looked out the window toward our barn and I saw a cat toying with a mouse. The cat would tease and torment the mouse then it would leave it alone, only to start the cycle again. The mouse never seemed to get very far. It seemed so unfair to me. I was so happy that I am not that poor mouse. I thought how awful that would be; to be tormented and not be able to get away.

All of a sudden, in a blaze of wonder, I realized that CF is the cat and I am the mouse. I go along doing fairly well for quite a while. Next, out of nowhere, CF looms its ugly head and I don't do so well. That CF cat picks me up and slams me to the ground. It bats me back and forth, and holds me down with its powerful paw. After a while, it lets go and sits back and watches for a time. I feel so good and enjoy my time of comfort. Of course, that cat will pounce again.

How do we live with such uncertainty? Is there anything that we can do to make ours lives less unpredictable? Perhaps there is. Maybe we can find a way to take our minds off that darned cat. If we can forget about that cat, for even a little while, our lives may seem a little easier. More about this, later.

My back seems to be back to normal after the auto accident, so I can get back on the treadmill and try to get back into some kind of decent shape. (Is that enough use of the word 'back'?) Have I ever told you how lazy I am and that I hate to exercise? I would love to be a slug-a-bed that spends most of my time in a comfortable recliner with a good book. Since that really is not the best way to take care of myself, I guess I have to do some exercise.

I like to spend about 20 minutes each day on the treadmill. That is enough to get my heart going and to burn some calories. (You know that, unlike most people who have CF, I am not underweight. In fact, I am an obese, older person.) Exercising really helps to keep my muscles in better shape, which helps me to breathe better, which in turn helps my overall health. That sounds like a "win – win" situation to me.

I always have had troubles with my feet. I was born with high arches and the shoes that are available to women today just don't support those high insteps. My primary care doc referred me to a good Podiatrist, who prescribed custom orthotics for me. Let me tell you what a difference they make in my overall well-being.

The shoes I wear are not stylish, nor are they particularly attractive, but they do allow me to wear my orthotics and that allows me to walk much more comfortably. Since I can walk more comfortably, I can get better exercise. The exercises that I do with resistance bands help to strengthen my leg muscles and that helps with walking, too.

So, now that my feet feel better, I am more interested in what my shoes look like. Even I get tired of having to wear "sensible" shoes all the time. I want something with a little style and some pizzazz! Shoes that can hold orthotics will never be called stylish, and they definitely have no pizzazz. (Remember that the CF cat always is watching.) What to do, what to do?

KATHY RUSSELL'S "THERAPUTIC" POLKA DOT SHOES.

I'll tell you what to do…go out and get some shoes that you like and good sense be hanged. Could I really do that? I always am so compliant and feel such need to follow the doctors' orders. Also, will my feet allow me to wear a shoe that looks good? Ah, what the heck…let's give it a try. (Of course, I am not telling that to my doc!)

> *"Doing something that is totally frivolous can be so liberating. For me, it was getting a pair of totally impractical shoes. For you, it will be something else..."*

Three times recently, I had seen an ad for a pair of shoes that really intrigued me. I think they reminded me of a happier, more innocent time in my life. They were high heels, which I haven't worn in many years. They had platform soles, which haven't been popular since the days when I was wearing high heels. They had open toes and sling backs. They were covered in a brown satin material that had cream colored polka dots. All in all, they were totally frivolous shoes. I might have seen these shoes on a secretary on an old TV show, but I never would have seen them on an old woman. Oh, well, I am old and I can get them (and wear them) if I want to. So I did!

I decided that even if I never wear them, they bring me pleasure. I could put them in my office as decoration and be happy with them. Somehow, though, I do think I will wear them – at least once – at least for a short while. It will feel rather daring; a little like skipping a round of time on The Vest®. This can be a good thing.

It is so easy to get into the habit of doing all that we should do to maintain a certain level of health. We sometimes tend to forget that we have any control over this aspect of our lives. We begin to feel bogged down by CF. We no longer have a sense of being able to decide what we will do and when we will do it. We know that at a certain time we will inhale whatever meds we have to and then we will sit and use whatever form of airway clearance we find to be the most effective. We always remember that the CF cat always is watching.

I advocate doing all one's treatments and all the CPT and exercise that we are supposed to. This we do for ourselves. If we skip our treatments, we are the only ones that have to "pay" for it. We must learn to do things because they will help us to live the best life possible. At the same time, I advocate doing something that helps to let us forget (for a little bit) about that darned cat. Doing something that is totally frivolous can be so liberating. For me, it was getting a pair of totally impractical shoes. For you, it will be something else, but there is something that can let you feel free…if only for a little while. Try it, then let me know what you did.

I mentioned that I am old. I will be 65-years-old in April. That is quite an accomplishment when one has CF. I owe a lot of the credit to my mother. She was my advocate and primary caregiver for the first 18 years of my life. She made sure that I lived to adulthood. She died 16 years ago.

For the past 43 years, my husband has filled the role of chief advocate and caregiver. He is the one who spends hours on the phone with insurance companies or other providers. He makes sure that all the 'i's are dotted and all the 't's are crossed. He is amazing. I think he learned much of that from his mother.

My mother-in-law was a terrific woman. She raised five sons and never complained about having a house full of men. She always was very thoughtful and caring. On birthdays, she would send a check written in the amount of the person's age and enclose it in a card for them. When children were young, this was just a few dollars, but when they grew up, the amounts got rather sizable. She died nearly 24 years ago. I miss both moms to this day.

In honor of my mother, my husband, my mother-in-law, and all the other wonderful people in my life; I have decided to carry on the tradition of writing a birthday check in the amount of a person's age. But I am doing it differently. Instead of sending a check to others on their birthdays; I will write a check to USACFA on my birthday, in the amount of my age ($65, this next time). This will give me more pleasure than any gift that I could receive. It will help me remember those I love.

I know that not everyone can afford to send an amount of money that is equal to their age, but if you can – what a nice way for us to be able to thank our caregivers and loved ones. When your birthday rolls around, give it a thought. USACFA can use the help and it is an easy way to say thanks to those who mean so much to us.

So, as I think of that CF cat and the little mouse, I feel that I am a mouse that can "roar" at times. CF may try to bat me down, but I will lift my head and roar back at it, as long as I can. Of course, doing something totally frivolous, in the meantime, couldn't hurt. I hope you can find your equivalent to polka dot shoes. ▲

Stay healthy and happy,
Kathy

Kathy is 64 and has CF. She is a Director of USACFA. Her contact information is on page 2.

FOCUS TOPIC

ORGAN TRANSPLANTS

Top 10 Things I Know Now After Having Double Doubles!

By Tiffany Christensen

1. One of the most difficult circumstances for any human to bear is the unknown. Waiting for transplant is the ultimate unknown. Waiting is usually the hardest part of the whole process.

2. The time waiting for transplant is probably the longest period in a person's life when they are not "in the rat race." The rat race will begin again after transplant. Many people hope and work towards having this level of "nothing to do"; they call it a sabbatical. If you think of the waiting as a sabbatical, you can give yourself permission to use the time for inner work, planning and your favorite (or previously unexplored) leisure activities.

3. Transplant is a major event that is very mysterious until you go through it yourself. Because of all of the emotions that go with this process, being sick and the surgery, it is normal to cling to every word of the people who have gone before you. Listening to other patients may help you avoid potholes but, be careful; some patients might *be* a pothole. Compare not: no two experiences of transplant will be the same. Even for those who have had the transplant twice, the experiences are completely different. Even having the same body/mind does not equal having a similar transplant journey!

4. This is a time when patients and families need the most support. Some people will surprise you in how they step forward and some will surprise you when they step back. It may feel

TIFFANY CHRISTENSEN

like the ones who step back have abandoned you and let you down. More than likely, they love you very much and are ill-equipped to handle watching someone they care for go through such a difficult time. It doesn't feel like love, but it is.

5. Even for the most peaceful patients and family members, there will be hard days along the transplant road, pre- and post-. Sometimes, it can be difficult to share the deepest emotions with the people in the "inner circle." Sometimes you need someone slightly removed from the situation with whom to speak openly and honestly. Social workers and therapists can be an invaluable resource on this road. As a patient, if you don't process your fears and frustrations, you are putting even more strain on your physical body. As a caregiver, you will have a higher rate of burn-out and unhealthy stress levels. Don't bottle it up—find a way to let it out.

6. Don't forget that you are living today. Waiting for transplant often feels like your life is in a holding pattern. It is, in many ways, but your mind, spirit and relationships continue to evolve and grow, even as your body becomes weaker. Remaining conscious of That Which is Important can increase your quality of life.

7. Emotions are impermanent and can be influenced by your body's struggle. Try not to take them too seriously right away. For example, some people have moments when they feel like they would rather "give up". This is normal for someone who is dealing with end stage illness and the feeling will, more than likely, pass. Allow yourself the space to cry or feel blue, but keep in mind that infections, fatigue and shortness of breath can be physical triggers for an emotional reaction. Knowing this might take the edge off. If you can't get out of your funk, that's not unusual and you can consider various ways to treat this—medicine, acupuncture, therapy, etc.

8. The transplant experience can be complicated. Expect bumps in the road for the first year. There will be a learning curve about the new meds, symptoms etc. Be patient; it seems overwhelming, but it will become as routine as brushing your teeth. For the first year, don't make too many definite plans until things have stabilized. If you have a symptom, even if

> "As a patient, if you don't process your fears and frustrations, you are putting even more strain on your physical body."

it seems minor, tell the team. You might be surprised to find all of the nuances to post-transplant symptoms. All the while, keep focusing on your goals and reminding yourself that, "This too shall pass."

9. There are no guarantees for any of us, before or after transplant. Some people choose to cope with this through hyper-vigilance with germ management. Some people live life in fear of chronic rejection or missing a dose of immuno-suppressants. Some people focus on their perception of a solution, i.e. exercise, meditation, "living a normal life", etc. There is nothing wrong with any of these things; however, the only thing we can do is live a life we love so that no matter what happens, we have no regrets.

10. I am not illness. There is a part of me that is never sick, never tired and never scared. Separating "me" from my body is very helpful in coping with illness. I still can enjoy life, no matter my physical state of being. ▲

Tiffany Christensen is 35 and has CF. She has had two bilateral lung transplants at UNC Hospital. She is the author of "Sick Girl Speaks!", and is a professional public speaker. Tiffany also offers private coaching to CF and transplant patients. She lives in Chapel Hill, NC with her husband, Jason, and two silly dogs.

Mailbox

Once again it is time to renew my subscription to your wonderful publication, *CF Roundtable*. Thank you for all your efforts. They are much appreciated.

Judith Riley
Brooklyn, CT

Thank you to all you volunteers who contribute informative articles and help keep us up-to-date on the latest research concerning CF. Please accept my donation to help with printing and mailing costs for *CF Roundtable*.

Sincerely,
Joan Scheu
Piney Flats, TN

In reading your *Summer 2008* newsletter, it made me so much realize your financial predicament. It made me want to, more than ever, contribute for postage because of your wonderful and informed publication. Having CF with its increased financial burden, not having worked in over two years and now being on SSDI and Medicare; I am still, sadly, unable to contribute. I am hoping that in the near future your general finances improve, as I would sadly miss this publication.

Dave Berkenbush
Pequannock, NJ

Note: USACFA, too, hopes that our finances improve. It is our goal to continue to make CF Roundtable available to all who want/need it, regardless of ability to make a donation.

I find *CF Roundtable* to be full of much information that is valuable to CF patients trying to help him- or her-self. I have a suggestion for a future issue; request that patients send in a list of foods that they find detrimental to their health and another list of foods that they find are beneficial to their health. Perhaps you could tabulate these lists into the ten best and worst foods.

Best of health,
Tom Dillon
Sun City, AZ

Please find enclosed a check to help keep *CF Roundtable* and USACFA going. Wish it could be more; we really enjoy the newsletter!

Thanks for all your hard work,
Nylah & Jeff Lyman
Rumney, NH

Keep up the good work!

All the best,
Preston Campbell, III, MD
Executive Vice President for Medical Affairs
Cystic Fibrosis Foundation
Bethesda, MD

You CF adults are awesome! The newsletter you produce is excellent, informative, well written, attractive and high quality.

Best wishes,
Chuck Nelson
San Jose, CA

The 2008 US Transplant Games

By Paul Feld

It has been a couple weeks now since my wife, Kristi, and I returned from the 2008 US Transplant Games in Pittsburgh, but the memories are still very fresh in my mind. Since my first experience in 2006, in Louisville, I had anticipated, both mentally and physically, attending the games in Pittsburgh; hoping to do well and striving to win my first medal.

We found Pittsburgh to be a much different city than I had envisioned. With the exception of navigating its streets, we found Pittsburgh to be very inviting. Most of the hotels, convention center, football and baseball stadiums, and its many bridges were within a couple miles of each other. Once we parked our car at the hotel on arrival, we did not have the need to use it during the remainder of our stay. Shuttle buses provided quick movement to and from the convention center and Carnegie Mellon University, where track and field and swimming venues were held. Walking tended to be the fastest way of getting from here to there, as long as one had the aptitude of navigating a triangular city with high rises at street level.

By a wonderful quirk in Major League Baseball's schedule, it just so happened my beloved Cardinals were in town for four days to play the Pirates. On the first day a fellow transplant recipient gave his tickets to me so I could attend the opening game, which the Cardinals won 6-0. Thus, the trip got off to a wonderful start!

The US Transplant Games are an amazing event, where every emotion one has is somehow found, fed, and grown. I can always anticipate sadness, guilt, smiling, laughing, screaming, crying, cheering, and ultimately, exhaustion when it has ended. This year at the opening ceremonies, about 1400 athletes gathered by team and proceeded into the convention center amid applause and tears. Most of us should no longer be alive, yet we are realizing the thrill of competition no different than the athletes at Beijing will feel this summer. *(Editor's note: this article was submitted prior to the Summer Olympics.)* But even more exciting is the 1000 or so living donors or donor families that have also made the trip and chose to proceed in following us, knowing it was their gift or the gift of their family member that made our appearances possible.

PAUL FELD AND HIS BRONZE MEDAL.

The first day of competition consisted of a few swimming events at Carnegie Mellon. Kristi and I decided to take the bus ride over to the pool and see what was going on, while, of course, cheering on the athletes from Team St Louis. As we entered the swimming arena, my teammate Beverly was exiting with her family. She was dripping wet and around her neck she proudly wore one of the three medals she won. I was sorry we hadn't arrived a little earlier to catch her swim.

So Kristi and I scuttled upstairs where there were still a few open chairs and we could watch the action. As we sat down, the women were swimming the 500 meter freestyle event. I thought to myself, "500 meters! I tried swimming the 100 meter IM two years earlier and could barely finish. How could these people swim 20 laps at the speed they were moving?" When I saw who was swimming in lane 8, I could not believe my eyes. Ana Stenzel, who was just celebrating the one year anniversary of her *second* double-lung transplant, was gliding through the water with ease. I could not have imagined how she must have trained to be able to compete in a 500 meter swim event. Yet there she was, gracefully splitting the water with her gliding strokes. Already I'm tearing-up as I watch a friend continuing to battle - and winning.

The second day was also a big swimming day, but started early at 7AM with the 5K kickoff run – sort of the 'unofficial' athletic kickoff to the games. Hundreds of athletes and donors compete in this event, and you'll never see more camaraderie than in the 5K. Dozens of volunteers line the streets and registration areas, signing people in, handing out water or bananas or whatever one feels is needed for proper hydration and nutrition. Others are handing out T-shirts or water along the run route. There are walkers, runners and hybrids, and best of all, it's the one event where donors, donor family members, and athletes (recipients) can all participate together. Some are hand-in-hand, many are in tears, and

all are in conversation getting to know each other just a little more than they had before. It's truly one big, happy family.

I happened to complete my 'jog' in 39 minutes, hand-in-hand with a friend named Tina, at the finish line, smiling from ear to ear. I don't know Tina well at all, but we both remember crossing the finish line together two years earlier in Louisville. We say goodbye after the race, promising each other we'll do it again in two years.

> "My 180' throw held up for the bronze, and I had won my first transplant games medal! For me, I had reached my goal to bring something home."

Day 3 was track and field day, and I was about to get busy. One of the challenges of both the organizers and participatory athletes on track and field day is to stay on time, be prompt for your event, and say some prayers that events you are registered for don't overlap. I was registered for the softball throw, the 100 meter run, and the 200 meter run. What I did not know was that in my running events, there were 24 other athletes competing in my age group (50-59 years), and that we would have 'timed-heats' in the 100M and 200M events just to decide who reaches the final 8 for medals. The initial heats for the 100M were scheduled for 9AM, and my softball throw was scheduled for 10:30AM. I also wasn't aware there were over 30 athletes in my age group throwing the softball.

9AM came, and the field was flooded with 100M runners, and they ran in heats based on age group, youngest to oldest. Given I was in the 3rd oldest age group, and male, I was going to have to wait on the sidelines a while. This turned into an hour and 15 minutes before my run came up. I was going to have to run, and then jog over to the baseball field where the softball throwing was being held. I got my run in, and finished 3rd of 8 in my heat, so I knew it would be borderline if I made the final 8.

Kristi and I made our way to the baseball diamond where it was mostly utter confusion. The 30-39 year old males were still throwing, so we had a good 45 minute wait for our age group to have their turn. I ate a couple bananas and drank a lot of water. It was a wonderful 78 degree day, but in the sun you still can dehydrate easily. I was in the middle of the pack for my turn in my age group, and the very first athlete threw the ball so far, it let the air out of most of the other throwers. His throw was measured at 203 feet, just 2 feet off the world record for our age group. Geez, I thought, and all that practice I did…. I had been practicing this event for about 3 months up to the games, and knew that my range was about 55 yards, or, 165 feet, so I was one of the deflated competitors.

As the others took their turns, the competition steadily went downhill. By the time my turn had arrived, 2nd place was 180'3". My first turn was a horrible throw, and it only measured 143'. On my second throw, however, my timing was very good and I nailed it, throwing 180'7". I was ecstatic, but I also knew there were at least 10 other competitors behind me, and we all had at least one final throw left before our age group was done. The remaining competitors all fell short of 180', and then we began the final throw round.

The first guy again hit 203', and pretty much knew he was out of everyone else's league. The guy who was just a few inches behind me then came up, and he launched a great throw of 186', which put me in third. I had a good 3rd throw as well, but it was measured at 178', so I was still in third. My 180' throw held up for the bronze, and I had won my first transplant games medal! For me, I had reached my goal to bring something home. I have some special plans for that big coin!

Later that afternoon, I heard I had reached the finals in the 100M, finishing 7th in the time trials. I also had the 200M to run around 4PM, and it was the last event of the day for track and field. The 100M finals were scheduled for 3PM. I ran the 100M finals, did the best I could, and finished 7th. The 200M race saw the same result, where I made the finals, but finished 7th in my group of 24. I was extremely satisfied with my results, as I had not been able to practice running much prior to the games, since I had spent almost a week in the hospital with pneumonia about four weeks before leaving for the games. I wasn't even sure I could run 200M, but I suppose adrenaline took over.

The last day of the games is always a crowd pleaser when most every team puts a volleyball team in competition and the convention center lights up with volleyball matches and significant team partisanship. I was part of the seven member Team St. Louis volleyball team, and we felt well-prepared. We played Washington, DC, in the first round, and won 25-0, 25-2. In the second round, we had a tougher match against Team Arizona, but still won rather easily, two games to none. A few hours later in match 3, we played an even tougher Illinois team,

Continued on page 23

How To Put The Fun In Fundraising or,

All You Need To Know About Starting A Transplant Fund

Questions by Andrea Eisenman

Answers by Jerry Cahill

We all know that it is a big decision in anyone's life to start thinking about getting a transplant. Many of us know that beginning the evaluation process for bilateral lung transplant involves many factors: deterioration in health, being mentally prepared and having a good support system. Not many people know that starting a transplant fund is equally important.

Jerry Cahill has such a fund and currently is on the waiting list for bilateral lung transplant at NY-Presbyterian Hospital. He was so enthusiastic about it that I asked him some questions regarding the process of starting a transplant fund. Hopefully, this will be helpful for others who are considering transplantation.

What is a transplant fund?

Contributions are sent in to the National Transplant Assistance Fund (NTAF) and are held in regionally restricted funds to be used for uninsured medical expenses incurred by the patient. These funds are administered by NTAF, not the individual. People set up a fund through NTAF to help with the financial burden of the unanticipated costs that insurance does not pay for when you are going through a transplant.

How did you learn that there was a transplant fund?

While researching the Internet once I was listed for a transplant, I came across the National Transplant Assistance Fund (NTAF) (www.transplantfund.org) 1-800-642-8399

NTAF acts as the administrator of regionally restricted funds in honor of the more than 3,200 patients they serve. NTAF has a 25-year record helping patients to afford critical, but uninsured, medical expenses related to transplantation — helping patients, their families and communities nationwide to raise more than $57 million (to-date) for critical medical care, that otherwise may be unaffordable.

Anyone can start a fund through

JERRY CAHILL

NTAF, once it has been demonstrated that there is need and that the individual is working with a hospital or transplant center. A social worker or financial coordinator must fill out part of the NTAF application to verify this.

Setting up the transplant fund is very easy and painless. I originally thought about opening up my own fund like "Jerry's Transplant Fund", but that involves too much paperwork and legalities. NTAF makes it easy and stress-free. They handle everything for you.

Is the donated money tax deductible?

Yes, NTAF is a 501(c)(3) nonprofit charitable organization – providing tax-deductibility and fiscal accountability. People donating feel more comfortable donating to an organization versus an individual person. Contributors can be sure that their contributions are used for medical expenses only.

Is there only one transplant fund available? Are there more than one in the US?

Yes, a few; however, I have researched similar organizations like NTAF but felt very comfortable with NTAF. They were very informed, and made me feel at ease. It's a "partnership". NTAF is the largest financial assistance organization in the United States for transplant patients – providing almost twice as much assistance in 2007 as the next largest organization.

What can the funds be used for, exactly?

Medication, relocation … any medical bills related to CF/transplant. The full list of expenses paid include: health insurance premiums, medications, deductibles and Co-pays, transportation to and from the transplant center, relocation or moving expenses, temporary housing due to relocation, mileage, tolls and parking fees for transplant center visits, lodging expenses for patients and support person, uninsured transplant-related procedures, living donor expenses, and search fees for bone marrow donor match.

> *"fundraising has infinite possibilities through family, friends, community events – you just have to get started."*

How much paperwork is involved with getting funds for paying bills?

Simple! All you have to do is fill out an NTAF Fund Request Form and submit it along with your receipts/bills for approval.

How did you get started?

I got started by calling NTAF and speaking to a patient services manager, Judy Macgregor, and she explained everything in detail and made it sound so simple. – It was a relief!

NTAF assists with everything from how to fill out the initial application to payment and reimbursement of expenses/bills. NTAF has an experienced staff that is available to assist with fundraising guidance, event fliers and materials, as well as media assistance.

Did you feel awkward asking people you know for funds?

NTAF supplied me with a starter kit that explained the "how to" and that started the ball rolling. You would be amazed how many family members and friends were so willing to help out and form a little committee. People love to help out and be needed.

How did you explain to friends/family what the money was for?

In my case, I created a brochure that told my story. Since many people already knew about my illness, it was not a shock.

Many times, the NTAF patient services department will suggest to a patient and/or their family/friends/fundraisers to draft an appeal letter to the community, explaining their story and need for help.

Is getting funding possible only if you have a large family or many friends?

No – fundraising has infinite possibilities through family, friends, community events – you just have to get started.

Here are some examples of my fundraising:

- I arranged a high school reunion that included a battle of local bands. The event had raffles and auctions, with local restaurants and bars donating food/beverages.
- Local bars did a) karaoke night and b) Monday night football with entry fee and kegs of free beer that were donated by a specific beer company.
- My local track club did a 5k run with T-shirts (that were donated) and the entry fee was donated to my fund.
- The two high schools where I was coaching did what is called "dress down day" and you pay $5 to dress down and wear jeans – that money was donated to my fund.
- A local bike shop – I used to bike with the owner – sold raffle tickets to customers for a bike and that money went to my fund.

The bottom line is that your support team needs to be creative – ANYTHING & EVERY IDEA can work! If you believe in what you are doing and are passionate about the cause then the fundraising will work; but START EARLY!!!

How important has this funding been to you? How has it helped you?

Extremely important! Since I am still on the "list" as I await the transplant, fundraising is an ongoing thing for me. I still have huge expenses from CF and am currently on disability. I can fill out a voucher and submit it to NTAF to be reimbursed for medical bills not covered by insurance. I receive the reimbursement check within ten business days.

How much have you raised?

About $120,000 and growing.

When should someone start a fund?

Once the doctors start talking about transplant, I would start ASAP before you get too sick — and now, with the new allocation system, you may not have enough time prior to transplant if you wait. But fundraising can be done at anytime. NTAF helps patients to raise funds post-transplant as well.

Have you had your transplant yet?

No, I have not been transplanted yet. I started early so I can build up my fund and not have to deal with a lot of financial burdens that arise following transplantation. I think the transplant itself will be stressful enough.

If someone is on disability or governmental assistance, does this money go toward their monthly earnings?

Funds contributed to NTAF are not seen as income to the patient, because funds are disbursed only for medically-related expenses and are administered by NTAF. The money does not belong to a patient, it is held on behalf of a patient in a regionally restricted fund.

What would you suggest to others about getting started?

Call NTAF (1-800-642-8399) and speak to a patient services manager - TODAY! ▲

Jerry Cahill is 52. He currently volunteers with The Boomer Esiason Foundation. He is passionate about track and field and coaches two high school sports teams. He can be reached at jcahillBEF@aol.com.

Ten Years and Counting

By Colleen Adamson

I celebrated the 10th anniversary of my bilateral lung transplant on July 3, 2008. Yea! We had a wonderful time celebrating with my parents, brother, and family friends at a party at my parents' house. It was very special to be able to celebrate this wonderful anniversary with the people who, quite frankly, are a major part of why I have made it ten years. They gave me strength, support, and assistance when I needed it the most over all these years. This is not just my anniversary; it is my support system's anniversary as well, and I will always be grateful for their love and support.

It hasn't all been fun and games, of course. Over the years I've had my share of issues, but they haven't slowed me down! Please note that, of course, the transplant experience is different for everyone; so don't think you will necessarily have the same issues I've had.

Right after the transplant came the steroid-induced diabetes, including insulin shots, which, luckily, were not hard to get used to for someone who has been around needles most of her life. High blood pressure came next, and that meant another pill. I squeezed in a gall bladder-removal surgery the year after my transplant.

Next I had pneumothoraxes. After the first one, they put me in the hospital on oxygen and I recovered quickly. They kept happening, though. Turns out I was having catamenial pneumothoraxes (CPs), which meant that I was having endometriosis around the lining of my lungs, thereby causing tiny bubbles to form, essentially pushing down on my lungs every time I had my period. When I was lying down on my back I could actually hear the bubbles and I sounded like a coffee maker – really! I was put on continuous birth control pills to stop my periods, and the pneumos stopped. This condition was added to the list of rare diseases at the National Institutes of Health Office of Rare Diseases (ORD) in July 2006. Leave it to me to have rare issues!

SCOTT AND COLLEEN ADAMSON IN NAPLES, FLORIDA, IN FEBRUARY 2008.

Next came the sinus surgery, which went fine and really helped with sinus drainage. After that, came the pulmonary embolism (PE). They found that by accident on a CT scan, luckily so. Then came almost bleeding to death (unknown issue with the Warfarin I was taking after the PE). The ER doctor said I was so bad off that, if I had cut myself, I could have bled to death; and I was already weak from the loss of blood I had experienced. I had to have plasma for that issue.

Then my kidneys failed, quickly. Within a year of the kidney problems escalating, I was on dialysis. I lost 30 pounds in six weeks, and I really thought I was going to die. I cried when they told me I couldn't have salt anymore (I am very close to my salt shaker). I could barely stand, I was so weak. My hair fell out. Somehow I made it five months on dialysis and was able to get a kidney transplant from my best friend, Kelly.

Then came the skin cancers (no, I'm not done yet!). I had squamous cell carcinomas taken off of my nose and temple, and most recently off my head, with certainly more to come. My hands look terrible from having pre-cancerous spots burned off, with more popping up all the time. People offer me hand cream to get rid of brown spots on my hands! My hands are shaking more than they used to, and I can't remember anything!

I'm pathetic! Poor me! Not really.

To be alive to even experience these problems is a blessing. Also, knowing what I do now about all of the side effects and problems, I would absolutely still get the transplant. I am alive today to admire a full moon, enjoy the beauty of a butterfly, walk my dog, spend time with friends and family, work, play golf, and travel. I am in awe of the fact that I now weigh 140 pounds, when I struggled all of my adult life to get over 100 pounds. I can breathe. I can walk up stairs. I am still alive. And even though the transplant resulted in some issues, to be alive is the best gift I could have ever received.

Thank you all organ donors, especially my organ donors and families, for the gift of life. ▲

Colleen is 49 and has CF. She is a Director of USACFA and is the Treasurer. Her contact information is on page 2.

See Me

Breathe in
Breathe out
Pump up, pump down
Balance
See me

Life leaps in every pore
Full strength showing
As pain becomes triumph
Where in sleep I drowned
The sound of wet breath
Now I rise on bellows wings
Lifting, pulsing, throbbing
Birth of flowing synergy
    Catch two, catch three, move on

Breathe in
Breathe out
Release, revive
Balance

Breath's Solstice,
Welcomes these lungs
With cool clean air
My scars once patchworks
On a barren field
Become eddies and ripples
Run through rolling muscle
    As ski slaloms round mountains
    Form a roadmap of life's journey

Breathe in
Breathe out
Hold on, live on
Balance

I am whole
I am One

See me

For Anthony
– Dolores Diprofio Creede

"Through the Looking Glass: Images of Adults with Cystic Fibrosis" and "Caregiver Stories" are projects of Breathing Room, a non-profit organization. Breathing Room hosts these and other projects to facilitate open and candid communication in the CF community, supports the development of a community of adults with CF and provides education and insight for families, caregivers, and medical professionals who impact our lives.

To learn more about us and view more images in the collection, please visit our website at: http://www.thebreathingroom.org

FROM OUR FAMILY PHOTO ALBUM...

JERRY CAHILL JOGGING WITH HIS OXYGEN ON.

ANDREA EISENMAN AND STEVEN DOWNEY ON THEIR WEDDING DAY, SEPT 13, 2008, IN NEW YORK, NY.

JOY HEINSOHN GETS READY TO RUN.

ISA STENZEL BYRNES (L) COLLEEN ADAMSON AND ANA STENZEL (R) ON A BOOK TOUR STOP IN SPRING 2008.

CYNTHIA DUNAFON AND STEVEN HOLLOWAY ON THEIR WEDDING DAY, MAY 13, 2008, IN CHICAGO, IL.

MAGGIE SHEEHAN AT THE CFRI CONFERENCE.

KURT ROBINSON GOLFING WITH HIS MOM (SHERYL FEWKES) ON HIS 25TH BIRTHDAY.

MICHELLE COMPTON AT THE CFRI CONFERENCE.

ALEX JENKINS AND RICH DENAGEL AT THE CFRI CONFERENCE.

Photos of Autumn

By Pammie Post

Fall is in the air, a refreshing welcome from the summer's heat and high humidity. Although it is only September 23rd, leaves slowly are beginning to reveal another coat of color. Foliage in Connecticut won't be at its peak until the third to fourth week of October.

Kayakers on Mirror Lake, Lake Placid, NY

Last September, Bill (my husband) and I went up to Lake Placid in the Adirondacks for a few days of R&R. Now I totally understand why there was a famous tuberculosis Sanatorium at Saranac Lake, not too far from Lake Placid. Upon our return, I told my pulmonologist that

anyone with breathing challenges ought to get a doctor's prescription to go breathe the Adirondack wilderness mountain air; so deliciously pure, untainted by toxic fumes or anything else. I noticed a big difference in my own lungs. If lungs can be ecstatic, mine definitely were.

Beauty surrounded us everywhere we roamed. Mountains spectacled with color loomed over the small villages. This photo was taken early in the morning when Mirror Lake (perfect name) was dead calm. The early morning light changes rapidly. There was no time to fetch my tripod from the hotel as the wind was beginning to pick up as well, as seen as a thin blue streak close to shore. I waited for the two kayakers to paddle into the image to add dimension and interest before clicking the shutter.

A View from a Hospital Window

To my delight, the fall foliage lasted three weeks

longer last year. Is this also global warming? Being in the hospital is never a picnic. Milstein Hospital, a part of Columbia-Presbyterian in New York City, is close to the

Hudson River, about 20 plus blocks south of the George Washington Bridge (GWB). The views on the Hudson side of the hospital are captivating 24/7. The scenery changes constantly.

Photography always helps me to recover or just feel well. It is with this knowledge that Bill brought my camera and tripod to my room. My surgeon told me that I could not lift more than ten pounds. No problem: Have hijacked wheelchair - Will travel. My journeys down to the ends of the hall became frequent, great exercise, too.

This photo was taken with a tripod (out of a dirty window) on November 17th at 3 pm. With an overcast day, the colors were enhanced. I waited for an Allied Van to cross the GWB to add another focal point of interest, create a diagonal line with the barge and the lighthouse and to connect with the fall colors below the bridge. The next day, with wide smiles and a little more energy, I left Club Med on the Hudson.

Oh, yes, pictured here is the celebrated and historic little red lighthouse. In 1942, Hildegarde H. Swift wrote a famous children's story, "The Little Red Lighthouse and the Great Gray Bridge". During the winter season, the lighthouse is shrouded in white plastic.

Praying Mantis on Salvia guaranitica or Black Blue Salvia

If you are patient and remain very still, close to a garden bed, you'll begin to notice all sorts of activity. As Bill and I were watching a Meadowhawk dragonfly perform handstands on top of another black blue salvia, Bill caught something move out of the corner of his eye.

Praying mantises always try to camouflage. They change their colors to either green or tan to blend into the plant material or background. With keen eyesight, they can spot their pray from 60 feet. This one had a mission with dinner in mind. A yellow jacket recently landed on the top bloom of the salvia. The praying mantis' stealth-like prowl had begun, very slowly, with full anticipation of success. Each step was calculated in a slow deliberate motion to ensure the stalk would not sway. Their balance is terrific. The sting-a-ling was toast, unaware of danger looming. I ran to get the camera. After the feast and much licking of its claws, the wee beastie descended with an air of complete and delicious satisfaction. This one was definitely smiling as it looked at the camera lens, a 105mm macro.

Until next time, happy shooting and relish the Fall Season with all of it colorful gifts. ▲

Pammie is 55 and has CF. She was a Director of USACFA for several years. You may contact her through cfroundtable@ usacfa.com.

Call to All Artists

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

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

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

FELD *continued from page 15*

and they beat us 25-4, 25-21. So ended the athletic competition for our team, but we walked away with 25 medals for our 28 athletes, and felt we did very well.

In Louisville in 2006, I was too exhausted to go to the closing ceremonies but did not pass up that opportunity in Pittsburgh. It was held on the sprawling campus of UPMC (University of Pittsburgh Medical Center), one of the finest places for healthcare in America. We took up random sections of the Pitt Panthers basketball arena by competing teams, and enjoyed a couple hours of fond memories covering that last couple days.

The National Kidney Foundation does an outstanding job of sponsoring and managing all the activities of the Transplant Games, and their photographers capture the true essence of the games: catching still photos of a 4-year-old running the 25 meter dash into the waiting arms of mom and dad, of an 8-year-old in the long jump landing flatly in the waiting sand with a huge grin on his face; or capturing the beautiful expression of a mother whose son had died recently – yet she was gently smiling toward the athlete her son had saved. This is what the games truly are all about. They are not about competition, but they are all about life.

I think once again about David, my donor. I feel his presence and satisfaction about the five lives he kept going through his contributions. And I think ahead toward Madison, Wisconsin, because in 2010, through David, I'll be allowed to experience this wonderful event once again. ▲

Paul has CF and had a bilateral lung transplant in 2004. He is a Director of USACFA and is the President. His contact information is on page 2.

CF: A "Marathon" Disease

By Joy Heinsohn

Today is my 33rd birthday, but on the day I was born I was expected to live only to my 18th. Of course, the life expectancy of people with CF increases every year, but it is going to take more than a statistic to tell me how long I am going to be around. I credit my good health to many things including: my strong will to fight; my persistence in doing *whatever* it takes to stay ahead of my illness including CPT, tune-ups and exercise; the support of my family and friends; and maybe being a bit hard-headed.

I love a challenge! Especially the challenge that begins with the phrase, "You probably can't do that because you have CF!" This very statement is what started me on my new quest two years ago when I watched my friend participate in a half marathon. The excitement and exhilaration in the air that morning stirred something inside me and told me to start running! In the past, people have said that someone in "my condition" could never run; at times, I could barely walk. But when a runner with prosthetic legs ran past me, I thought, "Hey, if he can do it, why not me?"

This is where my journey begins. I convinced one of my closest friends, who also has CF, to join me on a warm spring day for our first ever run. One might find this an easy task but, with 50% lung capacity, every step was a struggle. I began running for 10-second periods and then increased to 30 seconds and eventually was running two and three minute intervals. I had my good days and bad, as we all do with CF, but the changes my body and lungs were making seemed to be miraculous!

After running for almost a year, I completed a pulmonary function test and couldn't believe the results! My FEV_1, which measures the amount of force your lungs use on expiration, increased from 48% to 64%; I knew it was the running.

In April 2007, I completed my first 5K run and in March 2008, I completed my first half marathon- a whopping 13.1 miles! As I crossed the finish line and lowered my head to receive my medal, I felt like a warrior! Not only a warrior for finishing something that most people without CF couldn't accomplish, but a warrior against this disease that for most of my life has taken so much away from me, from my family and from my friends but now has given me the courage and determination to fight back and WIN! That day is something I will cherish my entire life and I hope that I can continue fighting until the battle is won.

My enthusiasm for running had seemed to spread, as many of my friends with CF now are on their own journeys and are feeling the same amazing effects. We run three or four times per week along the beach. Everyone says, "Good morning." as I run or walk past them, and most even stop to see if I'm okay when I am having a coughing spell. It is as though they, too, understand how doing something for your health, whether it's running or moving in general, can lift your spirits and make you stronger, both mentally and physically.

Running has become a huge part of my life, my health and even a way to fundraise for CF. Last spring, my sister, Sue, who does not have CF, called me and told me she was involved with a new non-profit organization called *Miles for Cystic Fibrosis*. I spent years fundraising for the CF community and for the first time in a long while, was excited about this opportunity. Founded by two Atlanta-based pediatric pulmonologists, Drs. Peter Scott and Steven Julius, who also happen to be marathon runners, *Miles for Cystic Fibrosis* raises money and awareness for the CF Foundation and local CF charities. The organization's mission is to honor CF patients who struggle with this "marathon" illness, and who require the same patience, strength and perseverance as running a marathon in order to stay healthy.

Miles for Cystic Fibrosis fielded a team – aptly named **65ROSES** — this past March in their 3rd annual run in the ING Atlanta Marathon and Half Marathon. Team members raised over $30,000 to support its selected CF-related charities. They will be taking Team **65ROSES** to the ING Miami Race on January 25, 2009, raising money and awareness for the CF Foundation and Reach for the Stars Foundation, a local charity that directly supports CF families. To become a member of Team **65ROSES** in the Miami or Atlanta races, to volunteer, or to make a donation, please visit the website, www.MilesForCysticFibrosis.org.

I am so thankful that I woke up early that morning to watch my friend run in a marathon because that day changed my life forever. I never will look at CF as an illness that I can't beat but as a marathon that I keep on running until I reach the finish line, a cure. ▲

Joy Heinsohn has CF and had her 33rd birthday on September 14th. She lives in Boca Raton, Florida. She enjoys spending time with her family and friends and, of course, running!

Information from the Internet...

Compiled By Laura Tillman

This issue brings a potpourri of articles from the Internet

LUNG TRANSPLANTATION

Lung Transplantation for Cystic Fibrosis: Ten Years of Experience. M.T. Aratari, F. Venuta, T. De Giacomo, E.A. Rendina, M. Anile, D. Diso, F. Francioni, S. Quattrucci, M. Rolla, F. Pugliese, V. Liparulo, M. Di Stasio, C. Ricella, S. Tsagkaropoulos, G. Ferretti and G.F. Coloni. Transplantation Proceedings. Volume 40, Issue 6, July-August 2008, Pages 2001-2002

Lung transplantation represents the only therapeutic option for patients affected by end-stage cystic fibrosis (CF). We performed 76 lung transplantations in 73 patients from 1996–2007. The mean time on the waiting list was 10 ± 6 months. The median follow-up after the transplantation was 69.3 months. Twenty-one transplants (27.6%) were performed under cardiopulmonary bypass. Perioperative mortality, excluding retransplants, was 16.4% (12 patients) and the causes of death were sepsis, primary graft failure, and myocardial infarction. The overall survival was 74.5% ± 5%, 62.9% ± 5%, 54.1% ± 6%, and 43.4% ± 6% at 1, 3, 5, and 10 years, respectively. The accurate selection of potential recipients and the correct timing of referral and transplantation are factors that play crucial roles to obtain satisfactory results in term of improvement of quality of life and long-term survival.

http://www.sciencedirect.com/science?_ob=ArticleURL&_udi=B6VJ04T3XF37-24&_user=10&_coverDate=08%2F31%2F2008&_rdoc=60&_fmt=high&_orig=browse&_srch=doc-info(%23toc%236080%232008%23999599993%23695129%23FLA%23display%23Volume)&_cdi=6080&_sort=d&_docanchor=&_ct=84&_version=1&_urlVersion=0&_userid=10&md5=0ae7b396ac481fbfd19f408be73960cf

Should lung transplant recipients routinely perform airway clearance techniques? A randomized trial. Prue E. MUNRO, Brenda M. BUTTON, Michael BAILEY, Helen WHITFORD, Samantha J. ELLIS AND Gregory I. SNELL. Respirology Published Online: 20 Aug 2008

Despite the widespread use of airway clearance (AC) techniques to clear excessive secretions and improve lung function, little is known about their efficacy following lung transplantation (LTx). This study compared the effects of two AC strategies (proactive vs reactive) on a range of clinical outcomes following

Continued on page 34

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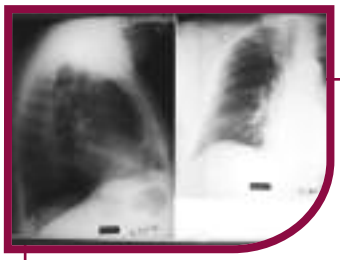


A DEEP BREATH IN
Getting Listed – Part 2

By Debbie Ajini

In the Summer 2008 issue I wrote about all the work that led to getting an evaluation for a double lung transplant scheduled at the University of Pittsburgh Medical center. This is Part 2 of my experience.

When I received my notice of evaluation they also sent quite a lot of information. They sent information on the hospitals I would be going to, as well as places to stay during my evaluation. They also included a sheet of testing that I needed to have completed before I went. Some of the tests just required me to get a printout of results (if I had the test done recently, like a mammogram and bone density test) while some involved going into my CF clinic and a lab for some tests. I needed to get some various blood work done, a hepatitis B vaccine and a few other tests. None of them were invasive and they were all relatively easy to schedule. Once I completed a test, I would fax the results to my Transplant Coordinator at UPMC. That way they had all the test results before I went there.

They had also sent me an itinerary of what I would be doing for the evaluation itself. It was very helpful to have this list beforehand, in case I wanted to research what a test was for. It was also helpful at the evaluation because there were many times we forgot where we were supposed to be. UPMC is made up of many hospitals so we did have to plan things out as far as when to eat, if we had time to go back to our hotel, etc.

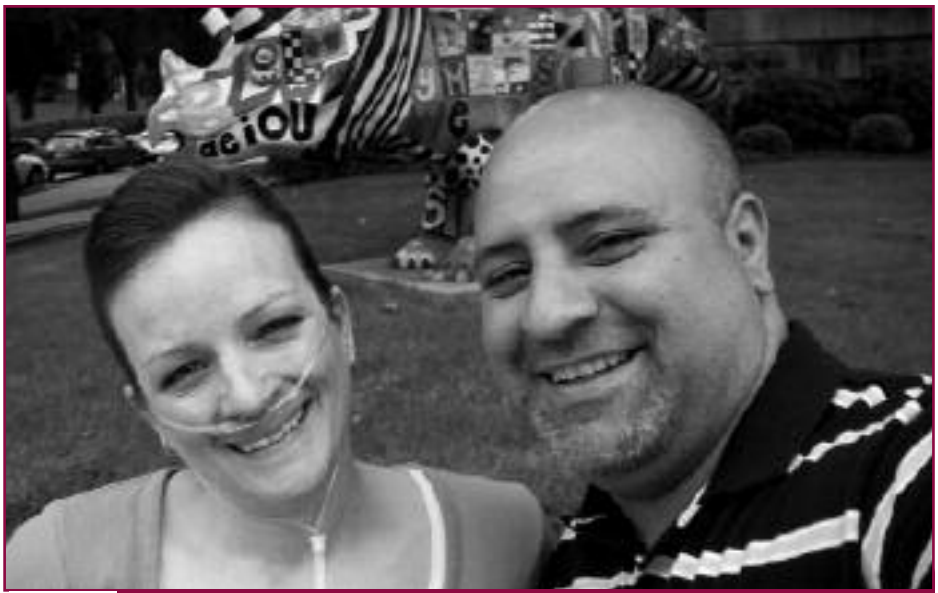
Luckily Pittsburgh was close enough that we drove, so arranging oxygen wasn't an issue; we just brought my supplies from home. The main thing I had to do was read the hotel information they had sent me and choose where to stay. The hotels in the area are very used to people coming from all over and they did offer a discount on the hotel and parking, which was nice.

My schedule covered four days, but none of the days was really long. I did have to get up early every day. We did have time to eat during the day and usually we were done by 2 or 3 PM. I was scheduled for quite a few tests, most of which I have had at some point in my life although a few were new to me, like my first arterial blood gas (it wasn't too bad!). I did PFTs, a six-minute-walk, lots of blood (only two pokes, but 16 tubes!!), a CAT scan of my lungs, an EKG and echo, a barium swallow, a VQ scan and a chest x-ray. We did not have to wait really long for any one test and none of them was very invasive or uncomfortable.

Part of the evaluation was meeting the transplant team; including the coordinators, doctors, a social worker and a financial person. On the first day the transplant coordinators did a preliminary interview and reviewed that we had our paperwork in order. After reviewing my chart the coordinator told me I was probably too healthy right now for a transplant. As I mentioned in Part 1 of this story, I was pretty sure that would be the consensus, but I wasn't 100% sure. So hearing that on our first day was kind of reassuring.

The last person we met with on the third day was the surgeon. We actually

> *"Yes, I know; here I am getting evaluated for a transplant and when the surgeon tells me I am ready, I freak out."*



DEBBIE AND LOUIE AJINI AT THE UNIVERSITY OF PITTSBURGH.

waited the longest to see him and it was a quick visit. After talking with me for about five minutes, he said he thought I was a good candidate and he felt I was ready to go now. WHAT??!!! Just when my husband Louie and I were beginning to feel safe, he dropped that bomb on us. We were a bit shell-shocked. Yes, I know; here I am getting evaluated for a transplant and when the surgeon tells me I am ready, I freak out. Over the next few hours I really thought about his words and the reality of that scenario. I knew this was a possibility of coming here, but that was the first time it really sunk in.

All that evening and the next morning, as we waited to see the pulmonologist, I kept thinking. I really reflected on the big picture and how, if they do say I am ready, that I am so lucky that a transplant center would agree to take me on as a patient. I reflected on all the CF friends I have known who died waiting for this chance. And I knew that I would trust whatever the decision was. After waiting six hours, due to a scheduling error, to see him I was ready to hear whatever he had to say.

He was very up front and honest with us about the transplant in general, and then, of course, how having Burkholderia cepacia (B. cepacia) brings other risks as well. I know two of his other B. cepacia patients. Both were transplanted. One survived four months and one is still going strong six months out. So, I told the doctor I was aware of the good and the bad. We sat with him for over an hour while he took a detailed history and did a physical exam. And he concluded our visit with the same sentiment the transplant coordinator had given me; that I was too healthy right now.

Louie and I were relieved. While we were prepared to go down the transplant road now, we are also elated we have the option of waiting. We know it IS down the road for us. But the longer we can wait, the longer I can keep my lungs as healthy as possible. The more time the doctors have to find out ways to improve the success rate, all the better, I say.

I received my "official decision" via phone about two-and-a-half weeks later. It was the same as we had been told by the pulmonologist. Right now, I am too healthy for a transplant. Aside from the B. cepacia, I am a good candidate. And as long as they continue to do B. cepacia transplants, they will do my transplant when the time comes. In the meantime, if my status changes my local CF doctor will notify them immediately. Otherwise, I will go back in a year for a checkup. Just to clarify…this is *GOOD* news. Many people I have told weren't clear on that. I had to remind them that the longer I can keep my original parts the better!

I am very comfortable with the decision. I am so glad we went and met the team. And I am glad they had a chance to meet me and see me in person. They can see me and my attitude about transplant but also just about having CF in general. They know I am an educated patient; I am a compliant patient; I am proactive in doing what I can to stay healthy; and I have a very good support network. All of these things are hard to see on paper. And all of these things make me a good transplant candidate. And now that they know me, they have a face to put with a name. And I am very grateful that as of right now, when I do need a transplant, I will have a chance. I am very lucky and I know it.

I guess it is a good thing I labeled these articles as "Parts" because now there will be more pages in my story of getting to a transplant. I just hope that Part 3 doesn't need to be written for a long, long time! ▲

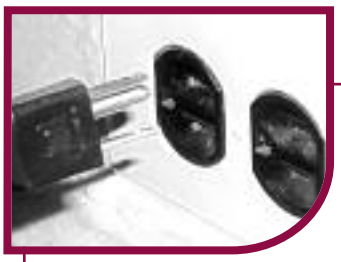
Debbie is 38 and has CF. She is a Director of USACFA. She and her husband, Louie, share their home with their yellow lab, Max. Her contact information is on page 2.

STENZEL BYRNES *continued from page 7*

future, and the belief that my voice matters. I decided to go online and write my congresspersons and request them to support legislation that would help me and thousands of others with CF and other chronic illnesses. This feeling is called empowerment. Empowerment is the best medicine for the spirit. No wonder the final convention benediction began with the words, "Eternal God…You ennoble our lives, by *empowering* us to do your work here on Earth, in creating a world of justice and peace for all."

I look forward to being part of the political process. I hope my reflections allow you to explore your patriotic spirit. Our election may have passed by the time you receive this newsletter, and I hope many of you shared your patriotism by voting. My proudest moment as an American was pushing my friend with oxygen, in a wheelchair, to the polls so she could vote, just two weeks before she was called for a lung transplant. If she could vote in her situation, any of us with CF can vote (there's always permanent absentee ballot for those with limited time and energy). And after the candidate is chosen, there is much work for us all to do. Political participation is good for your country, it's good for your health, and it's good for your spirit! ▲

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



UNPLUGGED...
With Rich DeNagel

By Richard De Nagel

Hello, everyone, and welcome to another segment of Unplugged! Time sure flies when you have a job, a milestone birthday, and a chronic illness. My summer and fall have been great, though life seems to be passing me by at high speed. I went to the CFRI (Cystic Fibrosis Research Inc.) Conference this year, and it was an intense, emotional, and incredibly informative event. I came away reevaluating many of my ideas about CF and how I integrate my disease and my life. This summer I also celebrated my 40th birthday. I never in a million years thought I would be alive at 40, especially considering that when I was born the average life expectancy for kids with CF hovered at around 14 or so.

With that in mind, I was surprised by my reaction to turning 40. I thought I would be excited, grateful and joyous; not even close. I was angry, resentful and all around surly. I was perplexed by this reaction, a feeling that only added to my anger. Shouldn't I be happy that I'm still alive? What do I have to be angry about? Aren't these feelings disrespectful to my CF friends who have died? What am I complaining about when they would've loved to have had a chance to do all that I'm doing now, and will do? I couldn't understand the anger.

Luckily, I have great friends, and one in particular (a guy who happens to be my roommate) suggested that I mix things up with "*Unplugged*" and let him interview me. And here we are. So, let me introduce my friend John Daigre; he's asking the questions and not letting me get away with much. Once again you get to read about my favorite subject: me! We'll pick up on my anger at the end of the column.

Hi, Rich, time for honesty.

1) How do you perceive yourself as a person with CF?

CF is a huge part of my life, and it takes up a lot of my time. In fact, it's on my mind most of my day; from when I wake up, to when I eat breakfast and take my enzymes. Then there are all of my breathing treatments and my chest PT. Actually, there isn't much time when it's not on my mind. Regarding my friends and family, I try to minimize what I'm going through, the challenge of having CF, because I imagine it's a lot to handle. I want to protect them from most of what I go through. A lot of times, I think CF has me.

2) I've noticed you compartmentalize your life a lot. What's up with that?

I compartmentalize parts of my life more than others. Like I said before, I try to protect people from what I go through. A part of protecting them is (surprise!) that I want to protect me. It goes like this: if they see all I do and go through, and all the problems I have, they will not be able to handle it and then they'll leave me. So if I keep my CF to myself, then I'll keep myself safe from being hurt. This idea applies to family, friends and romantic relationships. I think what you call compartmentalization is what I call protecting myself. And you and I know I'm not the only one who "compartmentalizes."

3) You've told me that you think people feel sorry for you. Any thoughts?

I am not sure what that's about. People who meet me for the first time hear I have CF and may say, "Aww, that's too bad." or "That's so sad." I wonder what they really think about my life. Even my family always wants to do things for me when I feel I can take care of myself. People have perceptions about me and CF without talking to me about it. I think I have some issues to work through on that front.

4) Do you sometimes feel sorry for yourself?

Of course I do. Having CF isn't easy and I have a lot to do every day. Some days are worse than others. There was a speaker at the CFRI Conference talking about compliance, and he suggested taking one day a week as a self pity day. Then letting your friends know about it, and encouraging them to call you and tell you how great you are. Then you get it out of your system and don't feel sorry for yourself the rest of the week.

5) My real question was, if you were going to ask for help, what would you ask for? I'll let you off the hook with an easy one: Why don't you ever ask for help?

I have a hard time with that. When I'm healthy I rarely give any clue that I might need, let alone ask for, any kind of help. I want to do everything myself and not be a burden. It's difficult because there are times when, without a doubt, I need help. But when there is even the tiniest possibility of me doing something myself, I'll do it. I guess this is something I need to work on.

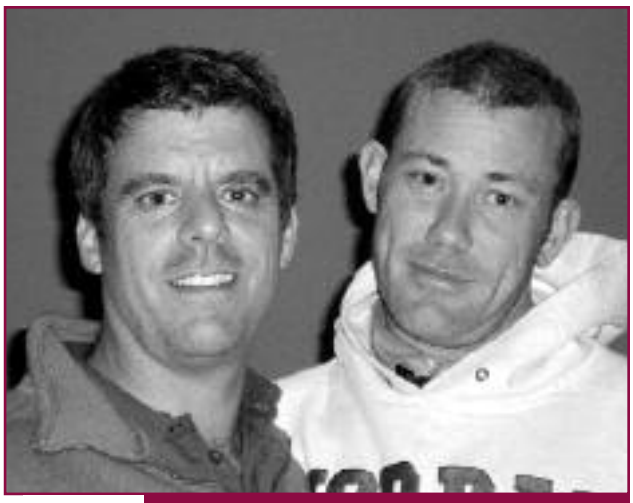
6) You look fit and healthy. Is it difficult to have a virtually invisible disability?

Yes, I guess. People never think I have any kind of disease because I look pretty "normal". So it does pose a challenge. As one doc put it, "You look great on the outside, but you're a mess on the inside". Don't judge a book by its cover. If I take a handicapped parking spot or disability seating on the bus people always stare at me.

7) This seems obvious, but I imag-

ine that brings up a lot of emotions?

Yes, it does. I feel a wide range of emotions in regard to my CF. Most of the time I see the glass as half empty. I struggle with taking care of myself, not to mention following doctor's orders. It feels overwhelming some of the time, which I guess is an improvement over it feeling overwhelming all of the time. I do get depressed a lot, usually over opportunities I missed or relationships lost. Both of which I blame on CF, which I realize is mostly not true. Are you getting that I have a tendency to blame everything on my CF?



JOHN DAIGRE AND RICH DENAGEL.

8) Anything good or upbeat?

No, nothing! Just kidding. Without a doubt, the people in my life, including you. CF connects me with so many amazing people, many of whom have CF, and other people with other diseases. I've also written about people in San Francisco who think I have AIDS. Interestingly, as a result I have met so many amazing people with AIDS. We connect over having some health condition and it is amazing. The good part of all of this is the huge amount of love I feel for people, and I cry sometimes thinking about the love in my life.

9) So, are you angry?

For many years I didn't believe I was angry, but through therapy I came to see how angry I actually was. And I was not just angry, I was full of rage. I was not expressing my anger, and just keeping it inside. I was drinking and doing drugs to excess, basically destroying myself. I was running myself into the ground and not doing my treatments. My therapist pointed out that people who have a strong sense of self worth and who love themselves do not try to destroy themselves. She said I had a patent disregard for my life; and she was right. It was hard to turn that around. I was so angry at having CF. I felt cheated and different and burdened. It was not fair. She said, "Who said life was fair?". But no one else has to do two hours of treatments before they leave the house in the morning. I wanted to blame someone, so for a long time I blamed my mother. My therapist then said CF was a trauma for everyone in the family, like a loss. We all had to deal with it. She said we had to talk about our feelings get them out, put them in perspective, then let them go. She was right. I have not finished this process of dealing with my anger, but it is better.

10) How about being scared?

I do get scared. I'm constantly planning my funeral or my burial. I'm scared I'm not going to get to do everything I want, and that my life will end sooner than I want it to. I'm not afraid of facing my CF physically or medically. I have other fears: like being sick, out of money, and alone.

11) So, considering your body as a temple to be well taken care of, why do you eat so much junk food?

First, it bugs you! But also I have a huge appetite and I love sugar. I know I need to work on my diet. I eat food that is not good for me. But I am eating.

This column was a good opportunity to throw out the old and explore something a bit more emotional. So that gets me back to my reaction to turning 40. Why was I angry? I think you might understand. With the help of my most recent therapist (yes, I'm still a big fan of therapy) I was angry for a few reasons. One, I did not think I would be here. In fact, I was sure of it, so I didn't make plans for the future. I've lived my life without ever thinking about the future. I never committed to jobs, relationships, or saved any money. I felt like I was lied to; and now I'm still here and don't know what to do with myself. Two, I have survivor guilt. Not to mention, I really miss some of these people. Third, I still have not made any goals or plans for my life.

Luckily, after a time the anger subsided and I was able to put things into perspective. I was lucky enough to have the option of charting a different course for myself. Today, I know I'm going to live for a while longer, without the guilt. So, I've taken steps to work again, and I know I want to be in a relationship with a guy who can handle my CF. I wanted to buy a car (and I just did!) and get a dog or two. I want to go to Paris. The good news is that today my life is about the future or, at least, I try to make it about the future, instead of waiting to die. My attitude is shifting and I'm in a whole new place with my CF. And I am 40!!

Thank you, to all who have written me about being *Unplugged*. I am still looking for more, so if you are interested in being interviewed please shoot me an e-mail! ▲

Rich is 40. He has CF and is a Director of USACFA. His contact information is on page 2.

"Strategies to Reduce Time for Airway Clearance"

Presented at the 2008 CFRI Conference by Mark Elkins, Ph.D.
Reviewed by Cynthia Dunafon

I don't think I have to convince many of you that the time it takes to complete aerosolized treatments can be onerous. Apart from the virtuous few who claim never to have missed their treatments (are they for real?), most of us settle into a less-than-perfect level of compliance that can be ramped up when exacerbations occur. But what if we could reduce the time we spend doing aerosols without compromising on compliance? Research physiotherapists like Mark Elkins are testing the way we inhale drugs, the efficiency of the machines we use, and key assumptions about airway hydration that drive many of the traditional "guidelines" for aerosol treatment in the CF community. At the CFRI conference, Elkins used research in his field to strategize about how we can do our aerosol treatments more efficiently.

As one might expect, he began by suggesting that we should review our drug regimen with our doctor(s) regularly in order to eliminate duplicate prescriptions or drugs that are no longer necessary, and make sure that our machines and devices are in good working order. He piqued my interest, however, when he began to focus on the details of our treatment routine: how long we nebulize each drug (and why), how much we dilute our drugs (and why), whether we combine aerosol treatments with other parts of our therapy regimen (and why), etc. The following highlights from Elkins' talk will illustrate how critical these elements are in assessing the efficiency of our aerosol techniques.

All milliliters are not equal.

How do you decide when you have finished inhaling a particular aerosolized drug? a. When the number of minutes suggested by the drug manufacturer for treatment has passed? b. When the nebulizer cup has gone dry? c. When mist no longer streams out of the nebulizer mouthpiece? d. When the phone rings? e. Some other criterion?

According to Elkins, nebulizers are not designed to aerosolize every drop of liquid you pour into them. A small volume of liquid, called the residual volume, remains in the cup below the atomizer. The premixed dosage for a drug such as Pulmozyme® or TOBI® includes the amount to be inhaled *plus* the amount that fills up the residual volume in the nebulizer recommended for use with that drug. So, do we need to spend an extra 5-10 minutes inhaling every last droplet out of the nebulizer? Probably not. That's the good news. But here's the rub: different brands of nebulizers have different residual volumes. For example, my Sidestream™ nebulizer has a wide, shallow base in the bottom of the cup, suggesting a larger residual volume than my LC Sprint™ nebulizer, which has a base shaped like the tip of a funnel. When a precise dosage matters and I've got a clean Sidestream in hand, I may want to lengthen my inhalation time or dilute the solution so as to decrease the percentage of the drug within the residual volume.

Don't dilute unnecessarily, however. You may need to dilute a new drug in order to tolerate it, but don't let a familiar routine keep you from making a timesaving change later on. Elkins suggests that we test our tolerance for troublesome drugs periodically, in a clinical setting if necessary, because our tolerances change with time and repeated exposure to the drug. I can vouch for this, as I've seen my tolerance for hypertonic saline increase significantly over the period of a few months. The more drugs you can manage at full strength, the shorter your aerosol treatments.

All hydration is not equal.

Many of us nebulize isotonic saline in order to hydrate the airways. In fact, we may grudgingly accept our lengthy inhalation times because we take hydration to be an end in itself – a benefit above and beyond the aerosolized fluid we need for proper deposition of a drug. Unfortunately, adding normal saline to the airway lumen via a nebulizer has no immediate effect on lung function and little or no effect on mucous clearance, according to a study cited by Elkins. Although he agrees that our lungs need hydration, as per usual, his focus is on a more efficient method. For Elkins, a major player in the landmark study on hypertonic saline in 2003, the body can do a better job hydrating the lungs through osmosis. When we are aerosolizing a few milliliters of hypertonic saline, our lungs will pull more fluid from the body to dilute the salt that has collected on the surface of the airways, than we could aerosolize in a reasonable amount of time.

All minutes are not equal.

Elkins described three studies that examined what percentage of a given drug patients inhale per minute during nebulization. In these studies, about 85-90% of the drug had been inhaled in the first 6-12 minutes, while the remaining minutes were spent inhaling only 10-15% of the drug. Are those last few minutes of treatment really necessary? By eliminating periods of slow nebulizer output, you could reduce your treatment time substantially and/or find time to squeeze in a second treatment later in the day with little net increase in time. (Remember that the rate of drug inhalation will vary depending on the machines you use as well as your breathing pattern and overall lung health, so check with your doctor first.)

Waiting periods between drugs or treatments may not be necessary. Waiting 15 minutes between taking a bronchodilator and starting hypertonic saline makes no significant difference in FEV_1 or in the amount of coughing from not waiting at all between taking these two drugs. Similarly, a study on DNase shows that inhaling the drug before doing CPT or the Vest® is just as effective, clinically, as inhaling the drug after doing physiotherapy. Why? Since DNase is a long acting drug, it keeps the sputum broken down for hours. Doing CPT immediately after a dose of DNase acts on the sputum that was altered by the DNase treatment taken some hours before, *not* on the sputum altered by the dose just taken. So, the waiting period often advocated between DNase and CPT may not be necessary.

Each breath may not be equal

Dr. Elkins also discussed some exciting areas of ongoing research. How do our breathing patterns impact how fast we inhale a drug? Could nebulizing in different body positions affect how the drug is deposited in different areas of our lungs? Studies like these will help us find new ways to make our therapy time as productive as possible and, in turn, motivate us to raise the bar on our treatment regimen – a state Elkins describes in Aussie fashion as being "switched on".

See Dr. Elkins' talk and accompanying slide show (available at www.CFRI.org) for more details, citations to clinical studies, and additional timesaving ideas. ▲

Cynthia is 44 and has CF. She is a Director of USACFA and the Vice President. Her contact information is on page 2.

CFRI REPORT

Review from the CFRI Conference… "Being a Parent When You Have CF"

By Maggie Sheehan

The CFRI Conference in August was the best I have been to in the four years I've been attending. The speakers were top notch and the subjects covered many great topics. The presentation I particularly liked was not one from a professional, but from a panel of our own titled, "Being a Parent When You Have CF".

As much as I have been told by my parents and CF team that I can do anything I put my mind to, having a child just did not seem like something I could accomplish. Although I still believe it would be very difficult for me to carry a child, mostly due to my deteriorating health status, this expert panel gave me hope; hope that I, too, could be a parent someday. Even though I know I may have the option of pursuing surrogacy or adoption, I came away from the discussion feeling more positive about my own chances of having a biological child.

There were six people on the panel, two fathers and four mothers. Some had chosen to adopt, some carried their own, and one family was able to conceive triplets using artificial insemination. I was very happy to hear some of the men could have their own children (using their own sperm) since we are taught that CF males are usually sterile.

While a few of the panelists had transplants and were raising their children during some of their own health crises, others were well into their 40s with no transplant in sight. It was remarkable to see how these people juggled their CF care while raising infants, toddlers or teens.

Raising a family while having CF may not be a desire or option for everyone. However, knowing it is possible is quite remarkable! I hope one day I, too, will be able to make that choice and share my personal story. Until then, I will keep adding to my baby name list! Let's see, there's McKenna, Declan, Merryn, Liam… ▲

Maggie is 20 and has CF. She is a Director of USACFA. Her contact information is on page 2.

CFRI REPORT

Improving Lung Function and Controlling Infection: Sorting Through the Options

Presented by Richard H. Simon, MD
Reviewed by Laura Tillman

Dr. Richard H. Simon, from the University of Michigan, discussed the problems of determining which treatment option should be used and when to start each, as well as a strategy for deciding whether a specific treatment is right for each individual patient. He presented a case study and then addressed continuing dilemmas.

Many treatment options for CF were cited, such as: Pulmozyme®, antibiotics, hypertonic saline, anti-inflammatories, chest PT, exercise, etc. The question that each physician must examine is - when is the right time to use any of the options and which one in each class should be used (e.g. Flutter® vs. the Vest®). In theory, treatments that work the best, have the fewest side effects, and have the best cost for value are the ones that should be chosen. However, there are inherent problems with this.

When choosing treatments that work the best, it may be that the only information available addresses whether the treatment is better than nothing at all; and that very few studies examine and determine which one of multiple treatments may be better. Thus, the only guidelines are that treatment A is better than no treatment and that it is unknown whether treatment A is indeed better than treatment B.

In choosing treatments that have the fewest side effects, it is difficult to detect uncommon but significant side effects, and known side effects must be balanced against the probable advantages of the chosen treatment.

In looking at the best cost for value, it's easy to measure money and time. However, estimating value is the difficult task.

Thus, when putting theory into practice the clinician looks at anecdotal experience, basic knowledge about CF and how the treatments work on the problem areas of CF, as well as the results of clinical trials.

Anecdotal experience comes from various sources, which may have drawbacks. *Personal accounts* as well as those from friends with CF have numerous variables, since CF has many ups and downs that may be totally independent of the medications being used. When using *Websites*, one has to know which are reliable. *Pharmaceutical and medical equipment representatives* have limited information and *experts* in the field need solid clinical information to support what they deem to be the best treatment options.

> *"Quality of life, compliance, and cost must be factored into the equation when deciding on a treatment plan for an individual."*

While knowledge of what goes wrong in CF and how medications work is helpful in matching treatments to the stage of disease where they should be effective, there often is ambiguity in the assignment of disease stage of a patient. This is due to the fact that the lungs aren't affected uniformly.

Clinical trials have their limitations as well, since not all trials are equal. Historically controlled trials are less reliable than random, double-blind, placebo-controlled trials. Dr. Simon then supplied the names of treatments which have the best data available. These include: Pulmozyme, hypertonic saline, aerosolized antibiotics, anti-inflammatories, and macrolides. Other limitations include the fact that conditions during clinical trials don't always reflect the real world, most studies don't compare similar treatments, and the trials do not always include the patients who

LAURA TILLMAN AT THE CFRI CONFERENCE.

may benefit the most from the treatment.

Dr. Simon then explained how hypertonic saline was studied: First, anecdotal experience from surfers in Australia was noted, then a scientific rationale for use was provided, followed by clinical trials and results of those trials. Based upon this, he went through a process of how a decision to use hypertonic saline for specific patients may be made. He discussed the entry criteria for the Phase III study as a guideline, which included age, clinical stability and FEV_1 equal to or greater than 40%. The problem with these guidelines lies in the fact that there probably was not a clinically relevant reason for choosing the age, there is no information regarding the viability of hypertonic saline for an unstable patient, and there is no information on the effects of hypertonic saline on patients with an FEV_1 below 40%. Thus, the caregiver must use subgroup analysis to refine which patients would benefit from treatment with hypertonic saline.

Another major consideration in choosing a treatment plan that often is neglected is patient preference. Quality of life, compliance, and cost must be factored into the equation when deciding on a treatment plan for an individual.

Dr. Simon concluded his presentation with a discussion regarding the predicament of choosing among the many treatment options within the same class such as: bronchodilators, chest PT, and aerosolized antibiotics, among many others. His final statement was, "Despite all the problems…what we are doing works!" ▲

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

CFRI REPORT

An Overview of the 21st Annual CFRI Education Conference

By Richard DeNagel

The 21st Annual Cystic Fibrosis Research, Inc. (CFRI) Education Conference was held in Redwood City, CA, from August 1-3, 2008. In addition to offering some great information, the conference also brought to mind a song - one I couldn't get out of my head. It's "Defying Gravity" from the end of the first act of the Broadway Musical "Wicked". The lyrics of the song are as follows:

Something has changed within me
Something is not the same
I'm through with playing by the rules
Of someone else's game
Too late for second-guessing
Too late to go back to sleep
It's time to trust my instincts
Close my eyes: and leap!

It's time to try
Defying gravity
I think I'll try
Defying gravity
And you can't pull me down!

I'm through accepting limits
'Cuz someone says they're so
Some things I cannot change
But till I try, I'll never know!
Too long I've been afraid of
Losing love I guess I've lost
Well, if that's love
It comes at much too high a cost!
I'd sooner buy
Defying gravity
Kiss me goodbye
I'm defying gravity
And you can't pull me down:
Defying gravity
With you and I
Defying gravity

They'll never bring us down!
(spoken) Well? Are you coming?

So if you care to find me
Look to the western sky!
As someone told me lately:
"Ev'ryone deserves the chance to fly!"
And if I'm flying solo
At least I'm flying free
To those who'd ground me
Take a message back from me
Tell them how I am
Defying gravity
I'm flying high
Defying gravity

The song tells the story of the Wicked Witch of the West and her evolution from a good little girl to the witch she became as an adult. As a kid, she was small, sickly and smart, and no one believed she would amount to anything. Ultimately, and particularly when she learns to fly, she shatters the limited expectations that others have of her. CFRI gave me the feeling that, while we live with CF, we can be and accomplish anything.

At CFRI, there was a pervasive energy in the air of hope and excitement. It was as if we decided together that we are not going to let CF beat us, and that we are going to *"defy gravity"*. We are going to change the way people think of us

Continued on page 34

DENAGEL *continued from page 35*

and CF by living full and productive lives. The spirit of the conference was living and thriving, and it seemed like everyone was represented; from CF parents to teens, adults and partners. As we all talked, ate and participated in the conference, we shared our experiences and our condition. Together, we wanted to fly.

The conference consisted of workshops, talks, scientific lectures, entertainment, support groups, food and fellowship! An excellent array of speakers addressed a wide range of topics, beginning with a focus on research supported by CFRI. Following that was a mesmerizing one-woman show, "The Permanent Me", performed by Tiffany Christensen. She gave a thought-provoking and emotionally charged performance. If you have not read her book "Sick Girl Speaks", I recommend it. The night ended with a presentation of the "Heroes of Hope…", a collection of exemplary and inspiring CF patients.

Saturday included one amazing, relevant and interesting talk after another. The first was by Dr. Richard Simon from the University of Michigan, who spoke about "Improving Lung Function by Controlling Infection." Using everyday, accessible language, he explained how to choose the correct therapy to help control your infection. He inspired me to want to do more to take care of myself! Other discussion topics included CFRD, sexuality and reproduction, and challenges related to parenting with CF. The afternoon was dedicated to support workshops, during which participants split into various groups. I joined the "adults with CF" group, though I secretly thought I should be a part of "adolescents with CF".

Sunday's lineup included more lectures, starting with a discussion of new and exciting therapies, led by Dr. Carlos Milla from Stanford University. The good news is that there are some promising developments on the horizon for CF treatment. His message: take care of yourself now because these new treatments can work only with the healthy parts of lungs. The next speaker, Dr. Mark Elkins of Royal Prince Alfred Hospital came all the way from Sydney, Australia. He spoke about reducing time for airway clearance, and I found his strategies to be the most meaningful and practical for my life, and for anyone living a busy life. I've since put his strategies to work and find myself to be both more compliant and healthier! The last talk of the day was from Joe Solowiejczyk, a nurse, social worker, and wonderfully sarcastic former New Yorker. He gave a hilarious and thought-provoking talk on CF compliance and how to achieve it.

Doing justice to the diverse and meaningful talks is a challenge, and I'm scratching the surface with the ones I've written about. And these are only the formal talks. I didn't even mention the informal exchanges outside, the talks over meals, and the too-many-to-mention touching interactions that were the essence of the conference. For me, the best part of the conference is the camaraderie between perfect strangers that leads to fast friendships on this journey called "living with CF."

That leads me back to the beginning, and "Defying Gravity". After it was all done I walked away with a bunch of new friends, a lot of new information, a new outlook on my CF, different ways to take care of myself, and a sense of hope that stuck with me. Keep that in mind next summer, or any time CF gets the best of you. CFRI is a sure bet for giving you a new lease on life! ▲

If you would like more info on the conference, go to: www.CFRI.org.

Richard is 40 and has CF. He is a Director of USACFA. His contact information is on page 2.

TILLMAN *continued from page 25*

LTx. A prospective randomized trial was conducted. Uncomplicated patients were recruited 1 month postoperatively.

Patients performed AC using positive expiratory pressure either twice daily (proactive strategy) or only in the presence of chest infection (reactive strategy). Lung function (FEV_1 and FVC), CXR (Brasfield score) and bronchoscopic airway characteristics (anastomotic healing, patency and secretions) were assessed at 1, 2 and 3 months postoperatively. Adherence was measured. No significant differences for any outcome were found between the two groups. The vast majority of patients had fully healed, 100% patent anastomoses without secretions at 3 months. There were no significant differences between the two groups in airway characteristics and the incidence of chest infection. Adherence to both strategies was high (84% proactive, 100% reactive). Proactive AC following lung transplantation was not associated with a reduced incidence of respiratory infection, alteration of CXR findings or improvement in airway characteristics.
http://www3.interscience.wiley.com/journal/121382679/abstract

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Clostridium difficile colitis in cystic fibrosis patients with and without lung transplantation. C. Theunissen, C. Knoop, C. Nonhoff, B. Byl, M. Claus, C. Liesnard, M.J. Estenne, M.J. Struelens, F. Jacobs. Transpl Infect Dis 2008: 10: 240-244.

Despite a large carriage rate of Clostridium difficile among cystic fibrosis (CF) patients, C. difficile associated disease (CDAD) is rather rare. CF patients who undergo lung transplantation are at a higher risk of developing CDAD and seem to present more often atypical and/or complicated disease. CDAD should be part of the differential diagnosis in case of digestive symptoms, even in the absence of diarrhea, and requires early treatment.
http://www.ingentaconnect.com/content/mk

sg/tid/2008/00000010/00000004/art00004

Impact of Burkholderia Infection on Lung Transplantation in Cystic Fibrosis. Susan Murray, Jeffery Charbeneau, Bruce C. Marshall, and John J. LiPuma. Am. J. Respir. Crit. Care Med. 2008

Transplant candidates infected with different Burkholderia species did not have statistically different mortality rates. Among transplant recipients infected with B. cenocepacia, only those infected with non-epidemic strains had significantly greater post-transplant mortality compared to uninfected patients. Hazards were similar between uninfected transplant recipients and those infected with B. multivorans. Transplant recipients infected with B. gladioli had significantly greater post-transplant mortality than uninfected patients. Once hazards for species/strain were included, lung allocation scores of B. multivorans-infected transplant candidates were comparable to uninfected candidate scores, while those of candidates infected with non-epidemic B. cenocepacia or B. gladioli were lower. Post-transplant mortality among CF patients infected with Burkholderia varies by infecting species. This variability should be taken into account in evaluating lung transplantation candidates.

http://ajrccm.atsjournals.org/cgi/content/abstract/200712-1834OCv1

NEWS RELEASES

Transave Announces Positive Phase II Results for Once-Daily Arikace(TM) in the Treatment of Cystic Fibrosis Patients Who Have Pseudomonas Lung Infections

Transave, Inc., reported positive results from a Phase II clinical trial on its lead investigational drug, Arikace (TM) (liposomal amikacin for inhalation). The compound is being developed for the treatment of cystic fibrosis (CF) patients who have lung infections due to the bacterium Pseudomonas aeruginosa. The Phase II data indicated that Arikace, delivered once daily for 28 consecutive days, produced a significant improvement in lung function, was well-tolerated, and had a side-effect profile comparable to placebo. The Phase II trial was a randomized, double-blind, placebo-controlled study of 64 patients from 15 centers in Europe. Arikace is a novel molecular entity comprised of the antibiotic amikacin, which is enclosed in nanocapsules of lipids called liposomes. Arikace was administered once daily for 28 days at 280 mg and 560 mg dosages, using a novel inhalation device, the eFlow® Electronic Nebulizer (PARI Pharma GmbH). The intent-to-treat analysis for efficacy demonstrated that Arikace, when administered once daily either at 280 mg or 560 mg for 28 days, resulted in clinically significant improvement in lung function at the end of treatment. This improvement was dose-dependent and was sustained at 28 days after completion of dosing, which was day 56 of the study. Pulmonary function (FEV_1) increased significantly among patients receiving the 560 mg dose of Arikace. Arikace was well tolerated, with no differences observed in the overall rates of adverse events or drug-related adverse events between groups. Fewer serious adverse events, pulmonary exacerbations, and hospitalizations were observed in patients receiving Arikace compared to placebo. Additionally, the time to receiving anti-pseudomonal rescue treatment was prolonged for the patients in the Arikace arm, as compared to those in the placebo arm, which further confirms the clinical benefit of Arikace. Arikace has been granted orphan drug status in the United States by the FDA, and has received an orphan drug designation in Europe by the European Medicines Agency for the treatment of Pseudomonas infections in patients with CF.

Altus Pharmaceuticals Announces Achievement of Primary Endpoint in Phase 3 Efficacy Trial of Trizytek for Cystic Fibrosis Patients with Pancreatic Insufficiency

Altus Pharmaceuticals Inc. announced today that its Phase 3 efficacy trial of Trizytek(TM) (porcine-free enzymes) in patients with cystic fibrosis (CF) successfully met its primary endpoint of improvement in fat absorption. The Company released top-line results from its 163 patient, double-blind, placebo-controlled trial of Trizytek, an enzyme replacement therapy for patients with pancreatic insufficiency. Trizytek is a stable and pure combination of three active enzymes in a fixed-ratio that is designed to improve fat, protein and carbohydrate absorption in pancreatic insufficient individuals. The trial met its primary efficacy endpoint with statistical significance. In cystic fibrosis patients with exocrine pancreatic insufficiency, Trizytek demonstrated a statistically significant improvement of fat absorption over placebo through the measurement of the coefficient of fat absorption (CFA). Patients treated with Trizytek had a statistically significant improvement in CFA compared to placebo. Trizytek has the potential to be the first porcine-free enzyme replacement therapy for patients with pancreatic insufficiency. Trizytek is intended to replace missing digestive enzymes with one capsule per-meal to promote and maintain proper digestion and growth in affected patients. Altus is developing Trizytek to enhance health outcomes by offering significant patient advantages such as improved and more consistent dosing that we expect will drive better long-term compliance. Utilizing recombinant technology, Trizytek is manufactured by blending three drug substance enzymes: lipase, protease and amylase. This consistent and pure enzyme combination is designed to improve fat, protein and carbohydrate absorption in pancreatic

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My Health 101

By Kurt Robinson

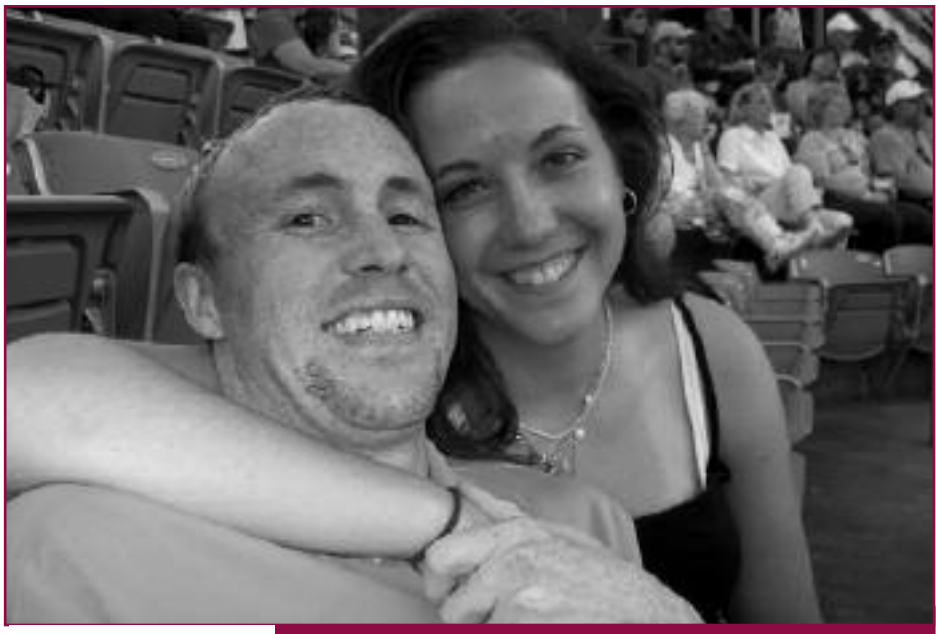
Another summer has come and gone. Although the weather would indicate summer is not over, the colder temperatures in the morning and the fewer hours of daylight tell me that fall has arrived. It was an eventful summer that was highlighted by my 25th birthday, a decent amount of golf (including quite a few holes I would like to forget), eating plenty of fresh berries, spending time with my family, friends, and girlfriend and, finally, a PICC line for several weeks and a few nights in the hospital to get a "tune-up". While the last "highlight" was something that I wish hadn't happened, I realized that it's just one of those things that I needed to have done. We're fortunate that we have the treatments and medications available to us to try to get our bodies healthier, even if it does come with several inconveniences.

Every time this Focus topic (Organ Transplants) comes around, I have a hard time thinking about what to write. That's because I never have had an organ transplant. I don't know what it's like to go through, emotionally or physically. I realize not every transplant is successful, but I also have heard incredible stories from fellow Directors and others with CF, as well as those who have had a transplant who do not have CF.

The closest I can get to any of this, and it isn't even remotely close, is having a "tune-up". This summer I was given the choice of having my PICC line put in and then staying in the hospital for a few days, or going home and doing everything on a home health care/outpatient routine. I chose home health care for many reasons. I wanted the independence and freedom to be able to administer my own medications. I, like many of us, don't like to stay in a hospital. I don't feel like I get adequate rest, there is always someone checking on me at all hours of the day and night, and the food gets old really quick. And lastly, I didn't want to miss any more time from work.

But after about ten days I realized I had made the wrong decision. My body hadn't responded to the treatments, my PFTs hadn't improved, and I knew I had only one option. It was one of the toughest days I have had in a long time. I cried for well over an hour after my doctor told me that I needed to be admitted that evening. I was frustrated because I felt like the ten days of home IV antibiotics were a big waste. I wanted to be able to spend the last few days of my girlfriend's summer with her before she started volleyball practice. But more than anything, I did not want to go in the hospital. My previous trip, about a year-and-a-half before, was not a pleasant one. It was the only time in my life that I can actually say that I was truly scared because I didn't know what was wrong with me. This time I knew it wouldn't be as bad and the doctors reassured me that this was just a tune-up and nothing like my previous hospital stay.

They were right. My body responded quickly and in a few days I was out of the hospital and back to my normal life. I realized that the next time I have to have a PICC line put in I should think twice about the reasons I want to administer home IV antibiotics versus going in the hospital. I know that I got a lot more rest in the hospital. I didn't have to worry about the stresses associated with having a PICC line and working at the same time. Nor did I have to worry about making sure to take the medications out of the fridge when I needed to or remembering all the steps for my treatments. That's why they have doctors and nurses. That is why they call it health care,



KURT ROBINSON WITH GIRLFRIEND, LISA MARTINI, AT A CORVALLIS KNIGHTS BASEBALL GAME.

because they are there to care for us and to do their best to get us better.

That begins with putting your own health as the top priority, even if it comes at the expense of a vacation, missing time from work, or some other obligation or fun activity. This can be hard for me to do because I never want to miss out on anything or make anyone wait just because of me. But sometimes we need to slow down just a bit and say, "It's going to be okay if I don't get do to this." or "Would you mind waiting a few minutes for me to finish my treatment?". Most people are more than happy to do so.

It is also very important to be an advocate for yourself while you are in the hospital. Ask plenty of questions. Don't be afraid to question a doctor or nurse when something doesn't seem right. I was lucky because my girlfriend was also an advocate for me while I was in the hospital. We both made sure that the nurses were administering the medications correctly. It is okay to have a doctor or nurse write down on paper what time you will be receiving your medications and approximately how long each treatment will take. While we all would like to think that we are the most important patient in the hospital, the reality is that doctors and nurses have other patients and sometimes (but not often) make mistakes, too, and if you (and/or someone else) can be there to catch these missteps then it benefits everyone. Don't be afraid to ask for more hours of uninterrupted sleep each night or to ask for food if you're hungry.

Remember that YOU are the one that needs to get better and YOU are in the hospital to get better. YOU can make a real difference in your health and health care by putting yourself ahead of everything else. The outcome can be a positive experience and you will be proud of yourself and ready to enjoy a hospital-free life again.

Since fall has arrived it is time for me to pack away the shorts, bring out the warm clothes, watch plenty of volleyball and football, get my flu shot, and be even more conscious about my health as the cold season approaches. ▲

Take care and keep smiling! ~Kurt

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

COVER STORY *continued from page 1*

about you. This includes allergies, previous bad reactions to anesthesia, and all medications you have been taking — even over-the-counter drugs, herbal preparations and vitamins.

- Insist that your surgeon write his or her initials or words such as "yes" or "this side" (in permanent ink) on the part of the body that is supposed to be operated on (for example, a knee). It's even a good idea to write "no" or "not this side" on the opposite body part.
- Directly before the operation, ask to make sure that every person involved with the operation knows who you are, what operation you are having, and on what side of the body.
- Ask about any new medication you may receive. Make sure it's what your doctor ordered.
- When you are discharged, ask your doctor to explain your treatment plan, including any changes in medications, restrictions on activity and any therapy you may need. ▲

Announcements

VOLUNTEERS NEEDED FOR STUDIES AT NIH

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

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

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

insufficient individuals.

TREATMENTS

Inhaled Mannitol Improves Lung Function in Cystic Fibrosis. Anna Jaques, BSc, MPH; Evangelia Daviskas, MBiomedE, PhD; James A. Turton, BSc (Hons), MBBS, MMedSc; Karen McKay, PhD; Peter Cooper, BSc, MB ChB; Robert G. Stirling, MB BCh (Hons); Colin F. Robertson, MD; Peter T. P. Bye, MBBS, PhD, FCCP; Peter N. LeSouëf, MD; Bruce Shadbolt, PhD; Sandra D. Anderson, PhD, DSc and Brett Charlton, MBBS, PhD. Chest. 2008; 133:1388-1396

The airways in patients with cystic fibrosis (CF) are characterized by the accumulation of tenacious, dehydrated mucus that is a precursor for chronic infection, inflammation, and tissue destruction. The clearance of mucus is an integral component of daily therapy. Inhaled mannitol is an osmotic agent that increases the water content of the airway surface liquid, and improves the clearance of mucus with the potential to improve lung function and respiratory health. To this end, this study examined the efficacy and safety of therapy with inhaled mannitol over a 2-week period. Mannitol treatment increased FEV_1 from baseline by a mean of 7.0%. Inhaled mannitol treatment over a period of 2 weeks significantly improved lung function in patients with CF. Mannitol therapy was safe and well tolerated.

http://www.chestjournal.org/cgi/content/abstract/133/6/1388

Good effect of IgY against Pseudomonas aeruginosa infections in cystic fibrosis patients. Elin Nilsson, MSc, Anders Larsson, MD, Hanne V. Olesen, MD, Per-Erik Wejåker, MSc, Hans Kollberg, MD. Pediatr Pulmonol. 2008; 43:892-899

This is an extended open study of oral prophylactic treatment with egg yolk antibodies against Pseudomonas aeruginosa, Anti-Pseudomonas IgY, of 17 Swedish patients with cystic fibrosis. They have been on prophylactic IgY treatment for up to 12 years and altogether for 114 patient years. A group of 23 Danish CF patients served as control. There has been a total absence of adverse events. Only 29 cultures have been positive for P. aeruginosa (cultures after chronic colonization not included), that is, 2.3/100 treatment months compared to 7.0/100 months in the control group (P = 0.028). In the IgY treated group only one pair of siblings (2/17) has been chronically colonized with P. aeruginosa compared to seven patients (7/23) in the control group. Atypical mycobacteria, S. maltophilia, A. xylosoxidans, and A. fumigatus have appeared only sporadically. There have been no cultures positive for B. cepacia. There was no decrease in pulmonary functions (P = 0.730) within the IgY group. Body mass index values were normal or close to normal for all IgY treated patients. In conclusion, Anti-Pseudomonas IgY has great potential to prevent P. aeruginosa infections.

http://www3.interscience.wiley.com/journal/121370141/abstract

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Once-weekly azithromycin in cystic fibrosis with chronic Pseudomonas aeruginosa infection. Steinkamp G, Schmitt-Grohe S, Döring G, Staab D, Pfründer D, Beck G, Schubert R, Zielen S. Respir Med. 2008 Aug 11.

Data on the effects of long-term treatment with azithromycin (AZM) on inflammatory markers in cystic fibrosis patients chronically infected with Pseudomonas aeruginosa are scarce. So far there is no pharmacokinetic and clinical data on once-weekly dosage of AZM in CF patients. In a randomised double-blind, placebo-controlled trial, patients received AZM or placebo 1 per week for 8 weeks (AZM dosage - 20-29kg: 500 mg, 30-39kg: 750 mg, 40-49kg: 1000 mg and >/=50kg: 1250 mg) after a course of intravenous antipseudomonal antibiotics. Pulmonary function tests, the serum markers LPS-binding protein (LBP), interleukin-8 (IL-8), CRP, P. aeruginosa alginate in sputum samples and quality of life scores were evaluated. Once-weekly azithromycin ameliorated inflammatory reactions and improved quality of life. A decline of pulmonary function after cessation of IV antibiotics could not be prevented.

http://www.ncbi.nlm.nih.gov/pubmed/18701270?dopt=Abstract

Improvement in clinical markers in CF patients using a reduced glutathione regimen: An uncontrolled, observational study. Alfredo Visca, Clark T. Bishop, Sterling C. Hilton and Valerie M. Hudson. Journal of Cystic Fibrosis. Article in Press

CFTR mutation, which causes cystic fibrosis (CF), has also recently been identified as causing glutathione system dysfunction and systemic deficiency of reduced glutathione (GSH). Such dysfunction and deficiency regarding GSH may contribute to the pathophysiology of CF. We followed 13 patients (age range 1–27 years) with cystic fibrosis who were using a regimen of reduced glutathione (GSH), including oral glutathione and inhaled buffered glutathione in an uncontrolled, observational study. Dosage ranged from 66–148 mg/kg/day in divided doses, and the term examined was the initial 5.5 months of GSH use (45 days of incrementally adjusted dose, plus 4 months of use at full dosage). Baseline and post-measurements of FEV1 percent predicted, BMI percentile, and weight percentile were noted, in addition to bacterial status and pulmonary exacerbations. Significant improvement in the following clinical parameters was observed: average improvement in FEV_1 percent predicted (N = 10) was 5.8 percentage points ($p < 0.0001$), average weight percentile (N = 13) increased 8.6 points ($p < 0.001$), BMI percentile (N = 11) improved on average 1.22 points ($p < 0.001$). All patients improved in FEV_1 and BMI, if measured in their case; 12 of 13 patients improved in weight percentile. Positive sputum cultures of bacteria in 11 patients declined from 13 to 5 (p <

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- Send your questions of a general nature regarding legal issues that relate to CF to our legal advisor: **Beth Sufian, Esq., 811 Rusk Street, Suite 712, Houston, TX 77002-2807**.

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0.03) with sputum cultures of Pseudomonas aeruginosa becoming negative in 4 of 5 patients previously culturing PA, including two of three patients chronically infected with PA as determined by antibody status. Use of a daily GSH regimen appears to be associated in CF patients with significant improvement in lung function and weight, and a significant decline in bacteria cultured in this uncontrolled study. These findings bear further clinical investigation in larger, randomized, controlled studies. ▲

http://www.sciencedirect.com/science?_ob=ArticleURL&_udi=B6X2D-4SJR2HD-1&_user=10&_coverDate=05%2F21%2F2008&_rdoc=13&_fmt=high&_orig=browse&_srch=docinfo(%23toc%237268%23999%23999999999%2399999%23FLA%23display%23Articles)&_cdi=7268&_sort=d&_docanchor=&_ct=34&_acct=C000050221&_version=1&_urlVersion=0&_userid=10&md5=34612e0064b8b493abf0a272511f3113

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

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

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

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

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