CF Roundtable
A NEWSLETTER FOR ADULTS WHO HAVE CYSTIC FIBROSIS AUTUMN 2010

New Law Helps People with CF Participate in Clinical Trials

By Beth Sufian, Esq.

On September 23, 2010, the U.S. House of Representatives passed the "Improving Access to Clinical Trials Act" (I-ACT). Passage of the I-ACT is a victory for everyone with CF, because it will help increase the number of participants in CF-related drug studies. The Cystic Fibrosis Foundation (CFF) led the efforts to make sure I-ACT became law. I-ACT had previously passed the Senate on August 5, 2010 and will now go to President Obama for his signature. The President is expected to sign the bill into law in October.

In 2004, CF Care Center physicians and people with CF called the CF Legal Information Hotline about issues people with CF were having with eligibility for SSI and Medicaid, after participating in CF research studies. Most CF research studies compensate participants to cover expenses such as parking, costs at the hospital, meals and time missed from work. Individuals who receive SSI benefits can receive only a small amount of income each month and still be eligible for SSI benefits. SSI benefits are only for adults who are low income or children who live in a household that is low income. Any money received by an SSI recipient is counted toward the SSI income limit. In addition, SSI recipients must meet certain medical criteria in order to be eligible for benefits.

Adults and children with CF who participate in clinical trials typically receive research compensation. Most hospitals would not allow SSI recipients to opt out of the receipt of research compensation because that would result in unfair treatment of patients who were low income. The SSI recipient who receives any amount of money in the form of research compensation will lose SSI benefits if the amount of money puts the person on SSI over the SSI income limits. When an individual loses SSI benefits he also loses Medicaid benefits. Sometimes it took years to have benefits reinstated.

The CF Foundation under the guidance of Suzanne Pattee, then a Vice President at the CFF, worked with attorneys, Beth Sufian and James Passamano, to determine if there was a way for the Social Security Administration to issue guidance, which would allow SSI recipients to receive a limited amount of money in the form of research compensation, without having the income affect eligibility for SSI benefits. However, the Social Security Administration determined there would need to be legislation passed in Congress, in order for people with CF to receive a limited amount of income from research compensation and still

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INSIDE THIS ISSUE

CF ROUNDTABLE
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EDITOR'S NOTES

Welcome to our autumn issue: the season of watching the leaves change, Halloween, hot-spiced apple cider and the start of the cold and flu season. Enjoy the fun stuff and check with your physicians regarding getting a flu shot.

This issue is packed with great articles and important information, starting with our cover story, by **Beth Sufian,** about a new law for people with CF that will help increase participation in clinical trials. **Jeanie Hanley** shares her experience in applying for the Pulmozyme Patient Assistance Program. This program helps people with CF pay their co-pays if they are not on Medicare or other governmental assistance. In *Ask the Attorney*, Beth Sufian discusses new healthcare reform and the Family Medical Leave Act. From the 2010 CFRI Conference Report, we have **Maggie Sheehan**'s article on "Pain and Posture", **Laura Tillman** reports on "Strengthening Couples in CF Families" and **Cynthia Dunafon** brings us news on the "UK Gene Therapy Update". All are items that people with CF might find of interest.

The Focus topic in this issue is: "Choosing the Right Caregiver." It is no surprise that people with CF believe that finding a good physician or caregiver is an utter necessity. These following articles say it all, starting with **Colleen Adamson,** who finds that her caregivers really do care or she gets rid of them. **Debra Radler** writes about finding "Dr. Wonderful," getting into a misunderstanding and then having to change doctors. She also discusses the fear of changing physicians and the compromise of adjusting to a new one. **Andrea Eisenman** discusses using alternative care practitioners and finding the right one, not always easy. **Bracha Witonsky** discusses changing CF centers and what qualities she looks for in a good fit. *In Speeding Past 50*, **Kathy Russell** writes about the importance of finding the right caregiver as we age with CF and the things she looks for in a doctor and CF center–all great recommendations.

We sadly say good-bye and fondly remember **Pammie Post,** a former director at USACFA who contributed to this newsletter even when she no longer was on our board.

The Breathing Room, a non-profit organization which produces "Through the Looking Glass" and "Caregiver Stories", seen on page 20, is looking for a new executive director. Please read about it on page 23.

In *Spirit Medicine*, **Isa Stenzel Byrnes** writes about the benefits of being mentally still. **Janice Tate,** in *Voices from the Roundtable*, writes about her struggle and search to find an answer: should she get listed for a bilateral lung transplant? **Patti Prince** shares her life and wants to offer support in *Conversation Corner*. In *Poetry Corner*, **Rachel Thompson** shares a poem called "Hospital Games". **Laura Tillman,** in *Information from the Internet*, lists new and upcoming CF medications and helpful studies in people with CF.

As they said to Humpty Dumpty, have a great fall!

– Andrea Eisenman

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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

Cara Brahm
Lebanon, KY
34 on September 10, 2010

Susan LeBoeuf
Laurel, MD
58 on August 11, 2010

Wedding

Andrea Eisenman & Steve Downey
New York, NY
2 years on Sept 13, 2010

Susan & David LeBoeuf
Laurel, MD
25 years on October 11, 2010

Valerie Vandervort & Rick Boyer
Claremore, OK
19 years on June 14, 2010

Transplant

Valerie Vandervort
Claremore, OK
Bilateral lungs
9 years on October 4, 2010

NOTABLE ACHIEVEMENTS

Andrea Eisenman, 45
New York, NY
Gold medal in tennis doubles
August 2010
U.S. Transplant Olympic Games
Madison, WI

Paul Feld, 53
Florissant, MO
Gold medal in long jump & Silver medal in softball throw
August 2010
U.S. Transplant Olympic Games
Madison, WI

Valerie Vandervort, 38
Claremore, OK
Bronze medal in 50 meter backstroke
August 2010
U.S. Transplant Olympic Games
Madison, WI

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) 2010: Choosing The Right Caregiver.

Winter (February) 2011: Sleep Or The Lack Of It. (Submissions due December 15, 2010) Do you have trouble sleeping? Is getting a restful night of sleep difficult for you? Do you know any tricks for getting adequate sleep? Please tell our readers of your experiences.

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

Summer (August) 2011: If Only I Had Known Then What I Know Now. (Submissions due June 15, 2011)

ASK THE ATTORNEY

Healthcare Reform and Family Medical Leave Act

By Beth Sufian, Esq.

The column this month will discuss questions about healthcare reform received after the last column, which gave general information on healthcare reform. There also is a detailed answer to a question about the Family Medical Leave Act. Nothing in this column is meant to be legal advice about your specific situation or is meant to suggest you change your insurance coverage based on any information in this column. If you have additional questions, please contact the CF Legal Information Hotline at 1-800-622-0385. The Hotline provides free and confidential legal information to people with CF, their CF Center care teams and their families. The Hotline is proudly sponsored through a grant from the CF Foundation. The Hotline can also be reached by e-mail at CFlegal@cff.org.

1. I will turn 22 next month. My parent's policy limits coverage to children under the age of 22. I read that under healthcare reform, children can now stay on their parents' policy until they turn 26. How can I continue my coverage?

As of September 23, 2010, children under age 26 can stay on their parent's policy, unless the child is employed and their employer offers coverage. Employers are allowed to delay covering children who have reached a limiting age under the policy until the policy is renewed. All insurance policies renew each year. Many policies renew on January 1st but some renew at other dates. If your parent's policy renews January 1, 2011, then the employer can decide to wait until that date to extend coverage to any children who have reached the limiting age on the policy. Some employers are allowing children who have already left their parent's policy, but are still under the age of 26, to go back on the parent's policy now, even if the policy renews at a latter date.

BETH SUFIAN

Insurers and employers are required to provide notice for the special open enrollment period, either when the policy renews or when the employer decides to extend such coverage. An employee who needs to have a child re-enroll in their policy should ask the employer when children under 26 will be allowed to re-enroll. For example: if a child reached the limiting age on a policy last year, then coverage for the child would have stopped. If the employer decides to allow children under 26 to enroll on the policy, then the employer must notify all employees enrolled in the plan that there is a 30-days period during which any children under age 26 whose coverage stopped will now be allowed to enroll in the policy.

If an employer purchases a new insurance policy for their employees after September 23, 2010, then the plan should allow children to enroll who are under the age of 26. However, employers do not have to offer coverage for dependents. If the employer offers coverage for *some* dependants, the employer must offer coverage to *all* dependents, regardless of the dependant's health.

2. My parent's employer only offers insurance coverage for employees, but no children are covered. Does the new law require the employer to offer coverage to children?

No. There is no federal requirement which requires a plan or issuer to offer dependent coverage at this time.

3. I read that the law requires insurance companies to sell individual policies to cover children under the age of 19. I am 17 and called to see if I could buy my own plan but was told the insurance company no longer offered any individual policies to children. Is that legal?

On September 23, 2010, the law requires insurance companies to sell new individual policies to children under the age of 19 regardless of their health. Unfortunately, in a move to

In 2014, all insurance companies will have to sell individual policies to any citizen.

get around the law, many large insurance companies have decided to not sell individual policies to children at all. The companies are not required to sell coverage to children. The law only requires those companies who do sell individual policies to children to sell a policy to a child regardless of health condition. Some states are considering legislation that would require insurance companies that offer family coverage to also offer child-only policies. No such state laws exist at this time.

The new healthcare law allows those insurers who will sell an individual policy to a child under the age of 19 to restrict enrollment of children under 19, whether in family or individual coverage, to specific open enrollment periods if allowed under state law. For example, an insurance company can sell child-only individual plans only in the month of January. An insurance company can do this only if there is not a state law that sets the timing and duration of open enrollment periods.

In 2014, all insurance companies will have to sell individual policies to any citizen. There will be subsidy programs that will provide subsidies to allow individuals who have low income to purchase a policy. Until 2014, adults over the age of 19 can be denied an individual policy based on their health. Children under the age of 19 will be able to purchase an individual plan regardless of health, if the insurance company offers such plans, but the company can restrict the months that such plans are sold. If a State requires continuous open enrollment or requires issuers to maintain an open enrollment period of a particular length or open enrollment periods of a particular frequency, then the State requirement will apply. The State law is not preempted by any current federal requirements. This means the state law which provides better coverage for citizens, such as requiring insurers to issue coverage to children under the age of 19, will be the law in that state. In such states, insurers cannot now say that the federal law allows them to restrict such coverage. There are only a few states that require guaranteed issue of insurance policies to children under the age of 19.

4. I need to take off one day-a-week for the next four weeks, because I need to have home IV treatment. I cannot afford to take off two weeks, but would like to take off two days a week from work while getting treatment. Can I use Family Medical Leave to take this time off?

First, in order to be eligible for time off under the Family Medical Leave Act ("FMLA") an employee must work for an employer who has 50 or more employees in a 75 mile radius. Second, the employee requesting leave must have worked for the employer for 1 year before requesting leave. Last, the employee must have worked 1250 hours before requesting leave. Employees who meet these three requirements are allowed to take 12 weeks unpaid leave to treat a serous health condition or the serious health condition of a spouse, child or parent. The employer determines when the leave period runs. Some employers give employees 12 weeks under FMLA in each calendar year. Some use a fiscal year and some give 12 weeks in the year after the request for leave is made to the employer. The FMLA can help people with CF, and their family members, especially if the person with CF is experiencing an exacerbation and needs to be hospitalized or to have home IV treatment. While an employee is out on FMLA leave, in most situations, the employee cannot have employment terminated. In addition, the health insurance the employee has, by virtue of being an employee, continues.

The FMLA allows people to take all 12 weeks at once or take intermittent leave.

As a general rule, family medical leave does not have to be taken in a single continuous period. In most circumstances, employees eligible for FMLA leave may take it intermittently or episodically; meaning in separate blocks of time rather than on a single occasion for a single qualifying reason. Eligible employees may also be placed on a reduced leave schedule, in which the employee's usual hours are temporarily reduced to accommodate an FMLA qualifying event. This interpretation of the law can be found at 29 C.F.R. § 825.203.

The distinction between intermittent leave and a reduced leave schedule is best illustrated by examples. An employee who requires periodic medical treatment for a serious health condition over an extended period of time may be entitled to intermittent leave. By contrast, an employee who needs to work fewer hours every day, to recover from a serious health condition, may be entitled to a reduced schedule.

The regulations permit an

Continued on page 21

SPIRIT MEDICINE

On Being Still with CF

By Isabel Stenzel Byrnes

As I write this, I have a view of my dog sitting just outside the screen door on my patio. It's morning, and the sun is bright. She sits with her eyes partially closed, head dipping, soaking up the sunshine. It's her morning ritual. My dog teaches me about the comfort of being still. As a person with CF, it's hard for me to sit still, and I can't help but wonder what role CF plays in this way of being. With CF, I've learned the importance of balancing times of action with times of stillness.

There are several kinds of stillness - physical, mental or spiritual. This article will explore how CF challenges us to *not* be still; and also how stillness can help us in our lives with CF.

Physically speaking, I find myself constantly in motion. Perhaps it was the albuterol, and now the prednisone, but whether it was sitting on my couch twitching my foot, joggling like a jackhammer with the vest on, exercising, or doing it a million times to pack it all in for a brief life, or exercising my lungs, my body is not used to being relaxed.

Throughout my life, I've been encouraged to be un-still. Mine isn't the only family told by doctors, "Try to have an active lifestyle-it's good for your child's lungs." So, hiking, walking, swimming and 'doing stuff' were part of my family culture. This physical activity has been a life-saver to shake up the mucus in my lungs. With CF, our lungs are constantly in need of being shaken up. If I could've earned a dollar for every hour spent shaking–with chest percussion or later, the vest–I'd be very rich! Of course, the most motion my body has been through has been during my heavy cough attacks, where every cell in my body is convulsing. And, the sicker I got, the more I sat in one place - but that didn't mean I was still. Even when I was confined in a hospital bed, I still did therapy; I still tried to exercise; I was still coughing. When I'd lie in bed, motionless, my chest was not still. I could hear the wheezes and gurgles, I could feel the rapid panting of my breathing. There was never true stillness.

> *"I reminded myself that no matter how my breath feels or sounds, if I'm breathing, I'm here, I'm alive. It's okay."*

ISA STENZEL BYRNES

CF is a very busy disease–we have to wash nebulizers, put out our pills, go to the doctor, flush ports–there is so much to do! And, with advanced CF, when being 'still' was less taxing than moving, I would often sit for hours at my computer writing e-mail after e-mail. Some of my friends with CF love to play video games. They can also sit in one place for hours, which, in theory, is being still. But is that really being still? No.

The focus here is on mental stillness. Mental stillness is imperative for spiritual growth. For the health of my spirit, I must find a way to rest my mind, my heart, my soul.

Mental stillness is much harder to cultivate than physical stillness. Just like sentences have a comma to make sense, our thoughts need commas to pause, reflect, and take a breath. All that matters in moments of stillness is that very moment. We don't have to worry, fear, plan, or do. It just is. To be truly still means to relax, to let things drop, to abandon, to withdraw, to refrain.

The other day I was introduced to a hypnotherapist. She led the group through a progressive muscle relaxation exercise to still the body, to imagine going down stairs to a beach, relaxing more and more, and clearing the mind of all thoughts except this imagery. It was very difficult! She called this hypnotic state in between asleep and awake, where you are still conscious but so relaxed your body thinks it is resting. She shared medical literature that proves that this

sort of relaxation–as well as prayer and meditation–can have positive health effects, like reducing blood pressure, pain relief, and improving oxygenation.

Stillness offers us the clear mental space to have an 'ah-ha' moment. Adults with CF have a burden of concerns: jobs, insurance, relationships, adherence, self-worth, how much longer we have… the list goes on. It's amazing how sometimes we have the answers to our problems deep inside of us, but they can be uncovered only during these quiet, meditative periods of reflection. I can actually remember the exact moment, when, late at night, lying in a dark bed, I finally accepted that I wanted a transplant. This peaceful stillness invited the answer to my next treatment option. Just as the sun and the moon are reflected in clear, still water instantly, true stillness invites *clarity*.

Mental stillness is a spiritual invitation. A well known line in Psalm 46 says "Be still, and know that I am God." When all is quiet, I can talk to God, or listen to my intuition a whole lot better than when I'm constantly distracted. I can hear wisdom, sent to me or cultivated from within, about who I am, or what path I should lead. "Being still in God" is spiritual serenity. It means having *trust* and *confidence* that you will be guided in your path, that you will be okay, no matter what.

So how do we do it, this stillness thing? We have to *want* to find stillness, to *intend* it. The first step to becoming mentally still is to become physically still. I've noticed when I lie in bed, or sit with my eyes closed, my thoughts go crazy. It takes a slowing down to finally become aware of just how noisy my thoughts always have been. Sometimes that can be scary. And being still means allowing those thoughts to come and go as they please.

I've always hated meditating, because of the focus on breath. Before my transplant, when I focused on breath, I'd hear my rapid panting, or my lungs' rattling sounds, and would become increasingly agitated and anxious. I found the best time to be still is after exercise, or after a treatment (but albuterol!), when my breathing was as relaxed as it could possibly be. And I reminded myself that no matter how my breath feels or sounds, if I'm breathing, I'm here, I'm alive. It's okay.

For me, I have a ritual. It's sad, but sometimes I schedule being still. I set my alarm clock 15 minutes earlier than I need to get up, then, in a sleep-awakening state, I just lie there. I don't think of my to-dos, but just stare at the ceiling and dwell in my comfort and peace.

The other night I was sleeping in a mesh tent near a lake on a camping trip. I could see through to the brilliant stars. The night was unbelievably calm. There was no sound, no wind, no buzzing of airplanes or anything electric. This forest, this lake, this dirt, just exists. It reminded me that nature, which to me *is* God, can be genuinely still. In nature, there is a time for rest and a time for activity. I relayed this to my life: there is a time to constantly go-go-go, but I also yearn for and need stillness. I can be both a human-*doing*, and a human-*being*. Like my dog teaches me, there is equal value in activity and basking in stillness. I hope that you may also find your stillness. ▲

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

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SPEEDING PAST 50...
Take Care When Choosing A Caregiver

By Kathy Russell

Well, it's almost autumn and I am still using 24/7 oxygen. I have a new portable oxygen concentrator (an Inogen G-2) that certainly makes my life easier. The batteries recharge much faster than the Inogen One and that makes a noticeable difference. Also, it is lighter and smaller than the old one and I like that.

Getting used to trailing an oxygen hose is a real learning experience. I managed to get my right foot caught in the tubing and fell onto my right knee – hard. Fortunately I have good bones and I didn't break anything. My knee is still sore and I can't kneel on it. I realize how many times I kneel on that knee and I miss the ability. I just need to be patient and wait until it is back to normal. At least I hope it will get back to normal. At my age, one never knows how things will heal. My doc said the X-rays look okay, so I have a good feeling about it. I am happy that my doctor is willing to let me heal in my own time.

No matter how old you are, choosing the right caregiver is important. When you get older, having the right caregiver is *vital*. As we age, our needs change and the problems of having CF are joined by all the problems of getting older. Having caregivers who listen becomes extremely important.

For many years I didn't see a "CF doctor". I did not hit it off, well, with the physician who was in charge of the CF Center that I had attended for many years. Evidently, our personalities were not compatible. I found that I was happier being treated by a local family practice physician. Also, that family physician was only ten minutes from my home, which is a distinct advantage when one is not feeling well. (The CF Center is about an hour away from my home and it is necessary to navigate a lot of city traffic to get there.)

This year, I started going back to the CF Center. There are a couple of new physicians there and they both seem to be good at listening. I find that listening is just as important for the caregivers as it is for the ones being cared for. If our caregivers don't hear what we are saying, they may miss out on important information and may even misdiagnose or mistreat our ailments.

> *"If our caregivers don't hear what we are saying, they may miss out on important information and may even misdiagnose or mistreat our ailments."*

KATHY RUSSELL

It has been my practice to interview any prospective caregiver. I make an appointment with the person and say that I want to interview him or her. Some appointment makers have almost scoffed at me, but most understand what I am doing and are quite willing to accommodate me. It doesn't take a lot of time to figure out if we will be able to work together to get me the best possible care for my CF.

I ask the physicians about where they trained, what specialized training they have had, where they have worked (and for how long,) what they feel about including the patient (me) in all aspects of planning my care, and (this is a big one) how easy it is for me to get in to see them.

That last point, ease of getting in to see them, can be a sticking point. It is not easy to get in to see some docs. They are booked up solid for weeks in advance. If I have an acute infection or sudden change in my level of health, I want to be seen now - not next week or later.

Many docs now are sending patients to urgent care centers or emergency rooms, when they need to be seen immediately. This is not acceptable to me. I don't want to be seen by someone who is unfamiliar

with me and my history, or worse, who is unfamiliar with CF. I refuse to accept "assembly line" medical care. Medicare, my insurance company and I are paying a lot of money for my care and I want our money's worth.

I think it is important to have a caregiver who keeps up on what is going on in the world of CF. If I know about a study or a new treatment, I want my doc to know what I am referring to when I ask about it. I appreciate having a doc who not only has heard of these things but is well-acquainted with them and can talk about them with some level of expertise.

When it comes to getting care at CF clinics, our choices can be somewhat limited. Some of us live where there may be two or more clinics from which to choose. Others of us have only one clinic near us and it may be an hour or two away. Still others live where the nearest CF clinic may be several hours away. We must decide if going to a certified CF clinic is worth the time and expense that it entails. Do we want to go there every three months, as the CFF would like, or will we go there only once or twice a year? Perhaps we will go anytime that we feel we are having an exacerbation. What we do will depend on our personal situations and what we work out with our doctors.

It is unreasonable for anyone to think that, because we all have CF, we all will fit into one set of rules and one way of doing CF care. Each of us is an individual and we will have individual needs. No CF clinic should tell you that you have to be seen on their schedule or they won't treat you. (Yes, I have heard of clinics making this type of ultimatum!) They need to remember that they are service providers and we are clients. Also, they need to remember that we are adults, not old children.

It is important that my docs for other parts of my care (not strictly CF care) know something about CF too. My podiatrist needs to understand about the high sodium and chloride levels in the perspiration from my feet. That perspiration can destroy leather and cause my feet to look as if I have been wading in the ocean. My podiatrist helped me to find a sandal (no tie shoes for me) that will accept my orthotics and still afford me some level of foot safety and support. My former podiatrist was not happy with the idea of me wearing sandals. I found a new doc, who would work with me and help me take the best possible care of my feet.

When I had a back injury, the spinal surgeon I saw understood about why I need to be able to cough. My back pain was impeding my ability to cough. (Every time I coughed, it felt as if a bullet was shot down the inside of my leg, so I tried to keep from coughing.) He understood that if I stopped coughing and failed to clear the mucus from my lungs, I might develop pneumonia and that could be very serious. He was honest about telling me that surgery might not help me. When I asked him if my back could get better without surgery, he said that it wouldn't. I asked if it might get worse and he said it could. As far as I was concerned, having surgery was a no-brainer. There was the possibility that it could help, while not having it meant that I could get worse. The surgeon, the anesthesiologist and I worked out a plan and I had a successful surgery.

> *"I think it is important to have a caregiver who keeps up on what is going on in the world of CF."*

Speaking of anesthesiologists, it is imperative to have anesthesia done only by someone who understands our needs. Their job is very difficult. We must be anesthetized enough to not move and to feel no pain, while being kept "up" enough to breathe adequately and not arrest. This is not a job for an untrained person. I always have insisted that I be able to talk with the person who would do my anesthesia. They might not like it, but they do it. I have not regretted insisting on it.

Many doctors are using e-mail and other forms of electronic communication to facilitate ease of keeping in touch. I have heard from friends who are able to e-mail with their caregivers on a regular basis and who find it helps their care. I know that my clinic has a system for checking one's records on-line. If one is e-savvy, this can be a real boon to good care.

No matter how you and your caregivers communicate, good communication is necessary. As I mentioned earlier, my docs listen. I try to listen to them and, I ask questions if I am unsure of anything that I think I have heard. They need to understand us and we need to understand them.

Another thing to look for in a caregiver is how good their cleanliness habits are. Do they clean their hands and their stethoscopes? Are the exam rooms cleaned between patients? Are all of the staff careful about cross-infection protection? Is everything clean? Is there good air circulation and does the air smell clean or have no smell at all? All of these things are important to our well-being. Some caregivers are offended when they are confronted about their cleanliness, but that is something that they will have to learn

Continued on page 21

The Pulmozyme Patient Assistance Prescription Program

By Jeanie Hanley, MD

Many patient assistance medication programs abound, a number of which have been highlighted in *CF Roundtable* issues. One of the more recent programs is the Pulmozyme Access Solutions Co-Pay Card Program. This program will cover co-pays for Pulmozyme prescriptions. All are eligible that are NOT covered by Medicare Part D, Medigap, GHPP or any other federal or state government insurance. The amount covered depends on the number in your household and income with a cap at $4000 maximum over a 12-month period. However, even those with very high incomes can receive co-pay assistance.

For those who are eligible, there are several steps to receive your co-pay card. First, access the online website at: www.pulmozymecopaycard.com or call 877-794-8723. If you are under 18 years of age, then you must have a parent or legal guardian call.

Once online there are three steps. I was able to complete these steps quickly and receive a Co-Pay card easily within minutes. The amount of personal information requested is: name, birth date, # in household, income, and whether your insurance includes any of the above restrictions. Once this information is given, voila! – your card is provided.

Once you receive your Co-Pay Card, then you must activate it by calling or going online again to basically confirm the information you have just provided. This is just a bit tedious (because you have to repeat the same information again), but well worth it, especially if you're eligible.

After activating my card, I learned that not all pharmacies accept it. In this case, request a reimbursement form from Genentech. If your pharmacy does accept it, then a prescription should be provided when you present your Co-Pay card. According to the website, this only needs to be presented once and the co-pay amount will automatically be deducted each time the prescription is filled.

It's important to note that the Pulmozyme Access Solutions Program does not cover the co-pay 100%. If you normally pay less than $30 for your co-pay, then this program would not be beneficial since it requires a minimum payment of $30 or 20% per prescription each month. But if your co-pay is $100 then this program would be beneficial since you would only pay the $30 minimum while the Co-Pay Card would cover $70. If the co-pay is $200, then you would pay $40 (20%). This program also does not cover anyone living in Massachusetts due to state restrictions on the use of discount cards there.

This is not a retroactive program; so prior Pulmozyme bills are not covered. Also, if you are not eligible, then you will be referred to the Partnership for Prescription Assistance, www.pparx.org, an independent organization that works with different manufacturers to help patients cover the costs of Pulmozyme and other medications. Also, the Cystic Fibrosis Foundation has the Patient Assistant Foundation, www.cfpaf.org with a similar purpose of helping those with CF cover medication costs.

One last note of encouragement is if you are not sure of your eligibility, then a phone call to them is definitely worthwhile. I called many times to clarify and verify the information for this article and was able to speak to a "specialist" fairly quickly each time. ▲

Jeanie is 48 and has CF. She is a Director of USACFA. Her contact information is *on page 2*.

USACFA Wants You!

Have you ever thought that you might like to be a director of United States Adult Cystic Fibrosis Assn. (USACFA)? Directors must have CF, must be at least 18 years of age and must live in the United States.

All directors must be willing to dedicate a few hours a month to USACFA business. Directors are expected to be active participants in USACFA, and to work on at least one committee (e.g., Fundraising, Nominating, Editing, or History). Newly elected directors serve one-year terms, while re-elected directors serve two-year terms.

USACFA holds elections of directors every year in the spring, so let us know if you are interested. Send your résumé, no more than one-page please, to: cfroundtable@usacfa.org.

keep their SSI benefits.

Mary Dwight, Vice President of Public Affairs at the CF Foundation, worked to obtain sponsors for a bill in Congress that would allow SSI recipients with rare diseases to receive up to $2000 in research compensation and still keep their SSI and Medicaid benefits. Attorneys at the CF Legal Information Hotline ("Hotline") helped provide information about SSI and Medicaid and met with members of Congress to explain the issues. The Hotline was able to identify adults with CF who had lost SSI benefits and Medicaid so that those individuals could share their stories with members of Congress. In addition, members of Congress heard from people with CF who were not able to participate in clinical research, because they knew they would lose their SSI and Medicaid benefits when the study was completed and they received research compensation. Thousands of people with CF sent e-mails to their Congressmen urging them to support the bill. Some families even visited their Congressmen and Senators in their hometowns to discuss the importance of the I-ACT.

There are currently over 30 research studies for drugs to help treat CF. At any given time there are thousands of children and adults with CF who may be receiving SSI benefits. This meant that a large number of people in the CF community were being excluded from participating in CF drug studies, simply because they were receiving SSI benefits. The CF population is small in comparison to many other disease groups, which already makes it challenging to find enough people to participate in research studies evaluating the effectiveness of promising new CF drugs.

The I-ACT legislation enables patients with CF and other rare diseases to participate in clinical trials without losing eligibility for public healthcare benefits.

"Because of this groundbreaking legislation, people with CF and other rare diseases will no longer be forced to choose between critical health care coverage and participation in research that could lead to the development of a cure for our most serious illnesses," said Robert J. Beall, Ph.D., president and CEO of the Cystic Fibrosis Foundation.

> "The I-ACT legislation enables patients with CF and other rare diseases to participate in clinical trials without losing eligibility for public healthcare benefits."

Cystic Fibrosis Caucus Co-Chairs, Representatives Edward Markey, a Democrat from Massachusetts and Cliff Stearns, a Republican from Florida, led the effort to pass the bill in the House. The House version of this legislation, HR 2866, had 141 co-sponsors. The CF community should be grateful for their efforts to have this bill approved by Congress.

"No one should have to choose between participating in a clinical trial and accessing the essential benefits they need. Today's bill will open doors of hope and offer the possibility of better health to those with rare diseases like cystic fibrosis. I am proud to partner with my friend and co-chairman of the Congressional Cystic Fibrosis Caucus, Congressman Cliff Stearns, in the passage of this bi-partisan bill, which now will be signed into law by President Obama. I also want to commend the Cystic Fibrosis Foundation for its incredible work on this vital issue. Today represents an important and hopeful milestone in the battle to beat devastating rare diseases that afflict millions of Americans around the country," Representative Markey said.

Representative Stearns said, "As co-chair and co-founder of the Congressional Cystic Fibrosis Caucus, I commend my colleagues for approving this legislation allowing people with rare diseases such as cystic fibrosis to participate in life-saving clinical trials that provide nominal compensation without the risk of losing their health care coverage. I also deeply appreciate the work of the Cystic Fibrosis Foundation in supporting my legislation."

To send a thank you letter to these two Congressmen for their efforts over an almost two-year period to get this bill passed, write their names and then U.S. House of Representatives, Washington, DC 20515 on an envelope, add a stamp and mail.

The Senate version of the legislation, S. 1674, was introduced by Senator Ron Wyden, a Democrat from Oregon, along with Senators Chris Dodd, a Democrat from Connecticut; James Inhofe, a Republican from Oklahoma; Richard Shelby, a Republican from Alabama; and Dick Durbin, a Democrat from Illinois who were the original co-sponsors. An additional 17 Senators were co-sponsors of the bill. To send a thank you letter to any of these Senators go to: www.senate.gov and click on Senators. There are different addresses for different Senators and also e-mail addresses.

If you have questions about research studies, please discuss them with your CF Care Center or go to CFF.org and click on clinical research, to see a list of different research studies being conducted at different CF Care Centers in the United States. Also you can register to receive legislative updates from the CF Foundation by going to CFF.org and clicking on, "Become an Advocate". ▲

Beth is 44 and has CF. She is a Director of USACFA and is the Secretary. Her contact information is on page 2.

FOCUS TOPIC

CHOOSING THE RIGHT CAREGIVER

Caregivers That Care

By Colleen Adamson

I love all of my doctors. I am not bragging, just being honest. They are all very considerate, intelligent, and helpful people, and most importantly, they keep me as healthy as possible. I am indebted to them all.

I had a bilateral lung transplant in 1998 and a kidney transplant in 2006, so you can imagine how many caregivers I have! I have had issues literally from head to toe. I tell people who see how many doctors I have that "it takes a lot of people to keep me going!" As you can see below, I have a lot of doctors, some that most people have, but not many people can say they have specialists for most parts of their body! I have the following types of doctors: podiatrist, orthopedist, lung transplant, kidney transplant, nephrologist, endocrinologist, gastroenterologist, dermatologist, dermatology surgeon, plastic surgeon, psychiatrist, Ear Nose & Throat (ENT), OB/GYN, neurologist, dentist, and optometrist.

Most of my doctors have been referrals from the Fairfax Hospital lung transplant clinic doctors and nurses, or referrals from those referrals. For me, this has worked out wonderfully – I have been extremely lucky. Every doctor they refer me to has experience with transplant patients, and they are really great doctors. By the way, as you read this article, you will notice I have a one strike and you're out policy – not a bad policy to have when it comes to your health.

When I needed a new dermatologist, the lung clinic referred me to a doctor who has a lot of experience with transplant patients. Perfect! My previous dermatologist was ok but couldn't handle anything complicated. He actually told me that in general, you can't get skin cancer on your head. He also told me that the bumps I felt under my eyebrow were nothing to worry about. That's the last I saw of him. I went right to the dermatology surgeon (also referred by the lung transplant clinic) and had major surgery on my eyebrow because the cancer had gone deep and wide. I lost half of my eyebrow and some of my forehead on that one. Luckily I have light eyebrows so I don't really notice that half of my eyebrow is missing. That's the least of my problems, really.

COLLEEN AND SCOTT ADAMSON AT A WEDDING, FALL 2009.

> "I love my doctors, not just because of how they treat me or how smart they are, but I have been fortunate to see some of the same doctors for a long time."

Interestingly enough, I also ended up with skin cancer on my head (despite always wearing hats when I'm outdoors). That was really major, because it covered a fair portion of the top of my head. It also involved two surgeries in two days; first day to remove the cancer, and the second day for the plastic surgeon to repair the wound. When I met with the plastic surgeon (referred by the dermatology surgeon) prior to surgery, he told me he would have to expand my skin to cover the wound – gross! He said he would use "balloons" under my skin for a few weeks to stretch my skin, and that I would look like Mickey Mouse and I should be prepared to wear scarves on my head for a while. I thought he was kidding. He wasn't. Luckily for me, though, he ended up not having to do that; he was able to pull my remaining skin over enough to cover the wound. Whew! Can you imagine going to work, or anywhere for that matter, looking like Mickey Mouse??

When I needed an ENT to close my tracheotomy hole after my lung transplant (I was on a ventilator prior to my transplant), again, the lung clinic referred me to an awesome doctor. He's very nice, calm, and intelligent. I saw another doctor at the same practice for sinus issues (at the time I didn't know I could have gone to the first ENT for that). She was terrible. She had me get a CT scan of my sinuses, and when I went back for a follow-

up, she suggested I get a CT scan of my sinuses. She didn't even bother looking at my chart, so she had no clue she had had me get one already, per her instructions! That is the last I saw of her. I asked my first ENT if he could be my doctor for anything ENT related, and he said he could. I've been happily and successfully seeing him for almost 12 years now.

I had to see an endocrinologist shortly after my lung transplant, because prednisone was causing my blood sugars to go up. Again, she was recommended by the clinic. I have been seeing her for about 12 years also. She is so wonderful. She is strict, but very caring and honest and supportive. She has trained me to know when and how much insulin to take, why I have to take it at certain times, how long each type of insulin lasts in my body, etc. I have had appointments with her where I will show up really upset or crying, and she spends the time to find out what is going on, and talks me through it. I always feel better after I leave her office. She is also the one who referred me to my excellent foot doctor. I had "trapezoidal" big toe nails imbedding into my skin so I had to have surgery to make them more square-shaped.

These are just a few examples of why I think my doctors are great. I love my doctors, not just because of how they treat me or how smart they are, but I have been fortunate to see some of the same doctors for a long time. They are like friends now, and I enjoy seeing them and chatting about what's going on in my life. Like I said, I always feel better after doctor appointments, not just necessarily physically, but also mentally and emotionally as well. I have caregivers that really care – you can't ask for more than that. ▲

Colleen is 41 and has CF. She is a Director of USACFA and is the Treasurer. Her contact information is on page 2.

CLUB CF ONLINE

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

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

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

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

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.

The Scary, Wary World of Shopping for a Doctor!

By Debra Radler

I used to think it was as simple as buying a new car. Once you've narrowed down the make and model, all you need to decide is the color. But now, choosing a doctor is no longer that simple. It seems as I get older and more seasoned in the workings of this disease, the person I choose to oversee my health needs has to fill some very large shoes—those of my expectations. And given the fact that it is my life I'm entrusting, let's face it, expectations run rather high. As time goes by, I've noticed that I view my doctor differently than I did when I was younger. Doctors used to be gods to me. Now they are, simply, people in the business of wellness. There is a huge difference in that mindset that has contributed to my becoming a much wiser, self-advocating patient.

DEBRA RADLER IN MONTEMARTE,IN PARIS, FRANCE, MAY 2010.

Many years ago, when I was a small child, my mother went on a pilgrimage to find a doctor who could diagnose me. She had great intuition about the failing state of my health despite multiple diagnoses from many different doctors to the contrary. My mom is not the type to take on a cause. You won't see her marching in the front line of any parade, but during that time in my life, when I was spiraling downward and no doctor could figure me out, I became her cause. We must have tried on a dozen or so doctors for size before finding the one for me, and by that, I mean the one for her.

There is no way that a clueless, little seven-year-old could know the makings of a good doctor. And honestly, my thirty-something mother probably had no idea either. After all, what do the healthy really require from a doctor? Not much. They have very little exposure and very little experience. They simply trust and believe that the person who stands before them, with his advanced degree and impressive vocabulary, is actually capable of diagnosing and healing. And very often, thankfully, that is the case. But sometimes it is not. And the fact that we saw so many doctors before one could diagnose my real problem exemplifies this point beautifully.

As fate would dictate, my savior came in the beautiful package of a young, handsome South American allergist. My mom finally decided on an allergist because so much of my upper respiratory struggles were due to severe allergies. Yes, I was quite the unhealthy specimen—skinny, drawn, pale—-with her sidekick chronic cough. Yet this man walked into the exam room, took one look at this buck-toothed little squirt, looked into my eyes and said "Hi, Beautiful." He had me at hello. The lollipop sealed the deal.

He had my mother at "I know what's wrong with her." His diagnosis of cystic fibrosis (CF) was less than glorious, and my mom might have regretted her pilgrimage at that point, but it was what it was, and, now, at least, we had a name for it. This allergist would become the first of two long-lasting, beloved saviors who happened to also be doctors. He remained a part of my life and health care for the next 15 years or so.

Did it matter that he was not a CF specialist, but an allergist? Did it matter that he was not abreast of all the latest treatments for those afflicted? I'm sure it mattered greatly, as there were many CF treatments that were not offered to me that should have been. Yet, I can't discount that he was the only one able to diagnose me, he had enough knowledge about CF to

realize that I would need constant antibiotic treatments to fight impending infection, and his expertise as an allergist offered me tremendous relief in my breathing. We felt comfortable and safe with him and my overall health improved. And when it was time for me to spread my wings into the world of CF specialty, I did so fearlessly, but not entirely. I kept my allergist as a backup physician, and continued to think of him as reigning superior over all others, for many more years, until I could find another to compare.

I saw a CF specialist for a few years in my teens and was put on the right course of CF care, and I changed to an adult pulmonologist in my early 20s. Neither of these doctors left lasting impressions and neither of them established a solid, working relationship with me. It was then that I slowly began to learn the importance of the relationship between patient and physician in controlling CF, and sought out to find someone who would have the same passion at improving and maintaining my health as I did.

When I married and moved to a new town, I wanted to find a CF clinic that was close to my home. That is how I happened upon the second of my two beloved doctors. It was the same feeling I had about my South American lollipop king—our personalities just jibed. Of course, I was no longer seven and I had become a bit more assertive, so he had to cut the CF mustard and be more than just someone I liked immediately. And from the onset, I felt that he did. He knew his stuff. He was an adult pulmonologist, new to adult CF care, and we grew up together in my disease, ultimately making a really awesome working team in fighting it.

He embodied everything I needed for that stage in my life. He was Dr. God, Dr Big Brother, Dr. Compassionate, and Dr. Hilarious. He had an impressive wit and morbidity about this disease that matched my own. It is hard to find people who can be really honest about the crappiness of this disease and what its future holds. Some people need the more Pollyanna doctor, I needed the realist. His rather maudlin approach to CF treatment fueled me to do everything I could to fight it and prolong the inevitable. And I appreciated his laid back, big brotherly handling of my extremely high-strung personality. He and I challenged each other's perspectives and each other's approaches, and respected the relationship we were building. He gave me a lot of latitude in managing my disease, trusting my knowledge in my own body, and offering his expertise when my body started failing me. I could gush on forever about all that he gave me over our 20 years together, including direct accessibility which remains unmatched in his profession. But all the gushing in the world would never do it justice. We just worked. I guess it is similar to falling in love with one person when you couldn't feel it for another person. There is a feeling that you get when you meet the doctor that is right for you. If there is one thing I knew with certainty, it was that I would never leave him, unless, of course, I happened to die on him.

> "The fear of change does not have to paralyze you. There are always choices. There is always another doctor, another team, another path to follow."

The funny thing about claiming something with certainty, though, is that one day we may have to eat our words. Last year I ate such words, and I did, ultimately, choose to leave my doctor. The sad tale of life sometimes unfolds unpredictably, and we are met with a crossroads or a hurdle that leads to a difficult impending decision. This decision was agonizing. My younger self would have laughed at how I agonized over it. But agonize, I did. My health had changed. The plummet came quickly and without advanced warning, and my health demands became greater.

During a particularly scary episode, an unfortunate incident occurred between me and one of his staff members, which I interpreted as hugely insensitive. He was not present for it, but he was informed later, and his ensuing mishandling of the situation led me to question his priorities, and the dedication of him and his support team in putting their patients' needs first. It was a completely subjective matter, interpreted differently by me than by him, yet the only interpretation that really mattered was that for the first time under his care I felt abandoned and alone in this disease, and he did nothing to assuage that feeling. He, in fact, fueled it. It was a very sad time for me both because of failing health and failing trust….not the best combination for someone battling a serious illness. I began to wonder if, perhaps, objectivity from a new set of eyes might actually benefit me more than the comfortable, little nest I'd built with my long-standing doctor.

I realized that I had come to a point in my life when I needed more than my Dr. Wonderful. I needed Dr. Wonderful, et al. So I went on a tenacious hunt for the et al., challenging my comfort zone to the point of break-

Continued on page 29

Needle In A Haystack

By Andrea Eisenman

I have always been a fan of Complementary and Alternative Medicine (CAM). I found it just that, complementary to Western medicine, also known as allopathic, traditional medical training. But finding the right caregiver was not always so easy. I usually found my alternative care providers through referrals by people who recommended someone. I did not realize that finding the perfect fit would be harder than finding an allopathic physician.

I know that I would not be alive today without the use of Western medicine: using antibiotics, enzymes, immuno-suppressants, insulin, various surgical implementations and so on. But to treat the whole body instead of partitioning it into smaller parts, I like the idea of CAM.

I started seeing an acupuncturist many years before my transplant when I kept getting sinus infections. And then yeast infections from strong antibiotic use. She was recommended by a friend who liked her but did not have CF. At first, this acupuncturist did not understand CF, or understand it in the way a Western doctor might. She saw it as heat and wind in one of my burners, or something like that. And dampness, which represented the phlegm. So, she needled me, which I found very relaxing and meditative and gave me a prescription for herbs that I had to buy in Chinatown that, when cooked-up in a crock pot, tasted like someone had vomited in it. It was gaggifying. I had to drink it three days in a row and then be off it for three days. Every third day, I came down with a cold—it was magical. She then put me on other herbs, that were in a pill form that had no taste, to treat the cold symptoms. After about five months of getting sick after drinking that concoction from Chinatown, I sat down with her and told her, I cannot do this to my body; every cold takes a toll on me. I asked, "Can you recommend someone whom you trust who has treated people with CF?" She did and I waited a few months to see this new person as I was not sure acupuncture was for me. A funny thing happened. I did not get sick for six months! Maybe that concoction was not all bad.

ANDREA EISENMAN RECEIVES ACUPUNCTURE FROM JACKIE.

So, when I decided to pursue more acupuncture, I went to a couple recommended by the first acupuncturist. I started seeing the man of the duo because the woman was too busy. She had treated a young girl who has CF and she did remarkably well. So, the husband would treat me but would confer with his wife for my CF. He did his best but by then, I was getting sicker and losing weight. He turned me onto the Neti pot for doing nasal lavage which helped my sinuses immensely, and he gave me ideas for gaining weight: shakes without milk but high in calories. I felt I was at least holding steady. I was taking herbs from him but only in pill form, no more cooking nasty herbal mixes. We had a better rapport about what CF was and I think he understood my reliance on Western medicine.

I now understood what to look for in an alternative practitioner. Someone who knew about CF. Someone whom I could converse with and understand, but also someone who understood me and could complement my reliance on Western Medicine.

It was many years after my transplant that I decided to go back into CAM. I was doing so well for many years but then I started getting sinus infections again and feeling tired all the time. I started seeing a reflexologist in Chinatown who made me feel wonderful for days afterwards. My friend referred him to me, she also did not have CF. He treated my sinuses and lungs through pressure points on my feet as well as points for my kidneys, liver, bowels, etc. He also did a Shiatsu type massage on my back and neck which took some getting used to—very rough at first. When I left there, I always felt centered and calm. When I would get home, I would do a nasal lavage and got out so much gunk from my sinuses, I knew it had to be working. He had no idea about CF or a lung transplant but he knew about clearing the body of junk and moving the chi around.

So, when a good friend, who has CF, told me about her acupuncturist, I told her I was happy with seeing my reflexologist. She told me how this acupuncturist, named Jackie, had saved her life when she had lived in NYC. I

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Rally 'Round CF Roundtable

USACFA, P.O. Box 151024, Alexandria, VA 22315-1024
Voice mail or fax: 503-669-3561
Email: cfroundtable@usacfa.org

Welcome to our second annual fundraising drive!

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

Fun Facts about CF Roundtable

- Started in 1990 by adults with CF
- All work is done by volunteers
- We currently have over 1300 subscribers
- No one is turned away because they are unable to afford a subscription
- People in 10 countries subscribe CF Roundtable
- Articles from CF Roundtable have been reprinted (with permission) in other countries

Money Facts

- It costs approximately $4.25 to print and mail each copy
- Out of our 1300 subscribers, only 500 are currently paid up
- The subscription price has not changed since 1990

PUBLISHERS OF CF ROUNDTABLE

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

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

Want a fun way to choose your donation amount?

- Donate your age in dollars—This is especially fun if you have CF because it is a great way to celebrate and honor every year!
- Pledge just $4.25—That will cover the cost of one copy. Or, if you can, send $8.50 for two copies!
- Give an additional $10 to cover someone else's subscription fee.
- Share any denomination you choose; we appreciate all support whether it be $1 or $1,000!
- Ask your friends and family to help you and send in a big donation.

Any donation above and beyond the $10 annual subscription fee is welcome. Every little bit helps us continue our mission of reaching out to adults with CF.

Remember USACFA is a 501(c)(3), non-profit organization, so any donation beyond your annual $10 (actual cost) is tax-deductible!

Detach this portion and mail your donation to: USACFA, P.O. Box 151024, Alexandria, VA 22315-1024

Name _____ I have CF ____ Yes ____ No

Address _____ City _____ State _____ Zip Code _____

Phone _____ Email _____

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

The USACFA Directors thank you for your continued support!

FROM OUR FAMILY PHOTO ALBUM...

RACHEL THOMPSON

ANDREA EISENMAN INHALES WHILE DOGS, ERNIE AND SCRUFFY, GET THEIR PETTING IN.

ADRIAN GULINSKI AND DEBRA RADLER AT A CHAPEL COURTYARD IN MONTMARTRE IN PARIS, FRANCE, MAY 2010.

CYNTHIA DUNAFON IN THE SWISS ALPS,

MEGAN HANSEN

SUMMER 2010.

Pammie Post

October 30, 1953 – September 13, 2010

Pammie Post, who was a Director of USACFA from autumn 1994 until spring 2003, died on September 13, 2010, at age 56. She had been battling chronic rejection, as a result of her bilateral lung transplant on October 10, 2000. During the almost ten years since her transplant, she had endured some really low lows and some true highs. She made it a point to make the most of every day.

Although Pammie had battled illness since she was about four months old, she was not properly diagnosed until she was age eight, thanks to the persistence of her mother. She learned to live each day to the fullest and to make the most of every day for the next 48 years.

Pammie married Bill Post in September 1978. They lived in New Canaan, CT and shared a love of boating.

She was on the board of the New Canaan Nature Center where she organized volunteers and ran its gift shop. She was a recipient of USACFA's Jacoby Angel Award for her many years of hard work on the Tony Fenton Bike Tour for Cystic Fibrosis (a big fund-raiser for CF) in Westport, CT.

Pammie also enjoyed gardening and she was active in the New Canaan Garden Club. She did wonderful photography for that club as well as for her country club and yacht club. She received many accolades and awards for her volunteer service and her photography.

During her tenure on the USACFA board of directors, she contributed stories and ideas that helped to enrich the lives of the readers of CF Roundtable. She loved to laugh and she made a special effort to bring laughter to others. Even after leaving the board of directors of USACFA, Pammie provided several cartoons for the newsletter. She made the effort to contact the artists and illustrators to get the necessary permission for CF Roundtable to reprint those cartoons.

Pammie also did a wonderful column on photography, which was accompanied by some of her beautiful photos and an explanation of the techniques she used to get those photos. She was a truly talented woman.

She never had an unkind word to say about anyone. When she found herself in an unpleasant situation, she looked for anything positive in it that she could find. She taught us how to live and how to laugh. Each time we see a funny cartoon or hear a funny joke, we will remember Pammie and we will smile.

We will miss you, Pammie.

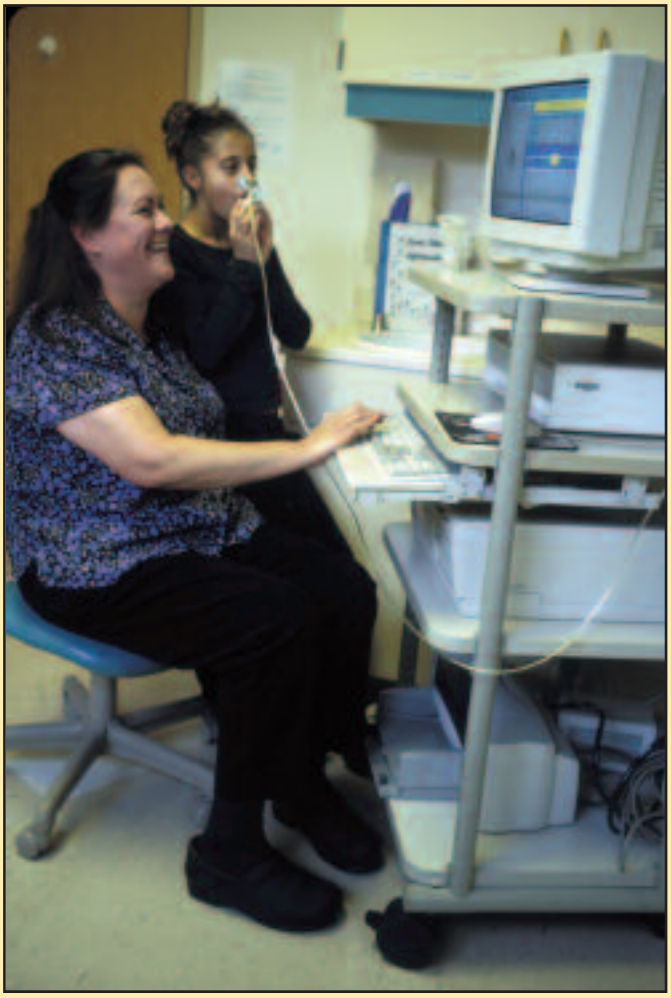

PHOTO BY ALEJANDRA CHAVERRI

Through My Eyes

Through my eyes

Touched by my hands
Nurtured by my words
Comforted by my smile
Encouraged by the sparkle in my eye
My heart has embraced many young lives
The memories are vivid, as is the pain
The paths taken: unique; the journeys: inspiring
Research rewards us
Hope sustains us

But, in the end- the final destination is always the same.

By Kristin Shelton

"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

SUFIAN *continued from page 5*

FMLA-eligible employee to take intermittent leave (or request a reduced leave schedule): (1) for treatment of a serious health condition; (2) to recover from a serious health condition; (3) to provide care for an immediate family member (child, spouse or parent); or (4) to care for a chronic condition.

When an intermittent or reduced schedule is requested for treatment of a serious health condition, the leave may be taken when medically necessary for the treatment of a serious health condition. Treatment may be planned or unanticipated but must be directed by or under the supervision of a physician or other healthcare provider.

An example would be chemotherapy or dialysis, which involve periodic treatments by a healthcare provider spread out over an extended period of time instead of a single continuing course of treatment. This reason for intermittent leave is described in the regulations found at 29 C. F. R. § 825.203(c). Some adults with CF may feel they need to work while receiving IV treatment but can benefit from taking a few days a week off while receiving IV treatment. This could be accomplished under the FMLA.

The FMLA leave may also be taken for recovery from medical treatment or a serious health condition. For example, an employee may take intermittent FMLA leave for medical checkups following surgery. Additionally, an employee may be eligible for a reduced work schedule following surgery if the employee is not yet sufficiently recovered to resume full time employment. This reason for intermittent leave is also provided for in the regulations found at 29 C.F.R. § 825.203(c).

The FMLA also permits an employee to take intermittent leave or be placed on a reduced leave schedule to provide care or psychological comfort to an immediate family member with a serious health condition. 29 C.F.R. § 825.203(c). To qualify on this basis, the employee must personally attend to the physical or psychological needs of the family member. 29 C. F. R. § 825.116.

An employee may qualify for intermittent leave if the employee or a family member suffers from a chronic serious health condition. In such circumstances, treatment by a healthcare provider may be periodic. 29 C. F. R. § 825.203(c). This is helpful when an adult with CF needs to travel a long distance to receive care from a CF Care Center.

While intermittent leave is allowed under the FMLA, many employers do not like it when employees take intermittent leave. It is important to discuss requests for intermittent leave and why the employee needs the leave so the employer understands the need for the leave. The employer can require documentation from the treating physician which explains why the leave is needed. ▲

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

In Memory

James Michael "Mike" Laird, 36
Baltimore, Maryland
April 19, 2010

Pamela (Pammie) Peyton Post, 56
New Canaan, CT
September 13, 2010

Janice Benning Tate, 46
Streamwood, IL
August 22, 2010

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

Send to:
CF Roundtable
PO Box 1618
Gresham OR 97030-0519.
E-mail to:
cfroundtable@usacfa.org

RUSSELL *continued from page 9*

to live with. It is the only way we can live and we have to take care to make sure that others take care for us, too.

Before I close, I have to mention that this is the fourth issue of our 20th year of publishing *CF Roundtable*. When we began, in 1990, we hoped that people would appreciate what we were trying to do. It seems that they have and do. I was middle-aged when we started. Now I am among the elderly and I am happy that I am able to continue to volunteer my time. I hope that others will decide to join us in our efforts to produce a newsletter that continues to be interesting to those who deal with CF on a daily basis. Adults who have CF are encouraged to send in their résumés to run for election to our board of directors. See page 10 for more information. Also, please check out our future Focus topics (see Looking Ahead on page 3) to see if you might like to write on any of them. We would love to read what you are thinking.

Be sure to talk with your doctor about flu shots, it's that time of year. ▲

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

Tips and Qualities I Looked for While Choosing a New CF Center

By Bracha Witonsky

When I first read about this topic, "Choosing The Right Caregiver," I immediately thought to myself, "Hey, I changed centers a few times, and I have lots of insights on that." But before I tell you them, I am writing this article to advocate for all of us CFers out there. Doctors reading this article, please bear in mind not to take anything personal. These are good important qualities to look for when looking to change your CF doctor or your CF center.

Choosing a regular doctor is so different from choosing a CF doctor. Your CF center will be your team that will get to know you and your family and friends. They will get to know everything about you, medically and non-medically, which together will affect you and your health. For example, whether you have a career or you are a parent, whatever your specific situation is, your CF doctor will need to gear your medical advice to yield to your special situation and to maximize your health. One big mistake that I can share with you is that I thought that since I had been at one center for many, many years (over 20 years since birth) I didn't have the option to switch CF centers. I thought that no other center will get to know me – who I am and all my personal needs. I had many good reasons to change, and thank G_d, I made the change. I will share with you the top five reasons that convinced me to finally make a change to my current center and Dr. Robert Giusti at NYU Medical Center, in New York City.

1. Like I said before, just because you are at one center for however many years doesn't mean that another center can't know you as well, and help you even better. You will be surprised how quickly they learn, if they have enough experience. They can make your life!!!

> "There is such a peace of mind knowing that your doctor is always available when you call."

BRACHA WITONSKY AND HER DOG, CIPPY.

2. Communication. This is the key word. Too often miscommunication lets you know that you are at the wrong place. For example: I would call my doctor's office, and leave a message for the doctor. The person who answered the phone would repeat my question to someone else, who repeated it to someone else. So then we had what's called BROKEN TELEPHONE. In other words, by the time my message got to where it needed to go, it was not the message I sent. So then when I got called back, I got medical advice to either start or stop an antibiotic – where really the doctor didn't hear the real question! This is very serious. This had happened too many times, and the office blamed it on a *miscommunication*. You could only imagine the frustration this gave me. You finally get a call back, and it's not the right answer!

3. Getting through to the doctor, literally; especially during office hours. There is such a peace of mind knowing that your doctor is always available when you call. Now, when I call to speak to my doctor, I hear, "Hold on," and before I know it, the doctor is on! Sometimes I don't even need the doctor, but I know he's always available to speak to me. I know that I am not his only patient, but somehow he is always available and that gives me a peace of mind. Being available at non-office hours for emergency situations is crucial. When it's after hours, the emergency line is very reliable and they always get through to the doctor - ASAP! At my old center, there was ALWAYS an excuse why the doctor didn't get my call!! Each time there was some other excuse, while I was in a crisis! It's just inexcusable in an emergency for your doctor not to call you back. We do have patient's rights. Knowing us –a nything in our bodies can become an emergency and knowing Murphy's law – it always happens after hours!

4. Availability when making an appointment. There are two kinds of

appointments to make. One is a sick appointment and you should be able to make that appointment for that same day, ASAP. The other appointment is a well appointment. This should be made for a time that is mutually convenient for both the office and yourself. (I say convenient time, because some of us work, or some of us are parents and need to work around the kids' schedules.) My doctor has the luxury of having two offices; one in Brooklyn, and one in Manhattan. They always fit me into their Brooklyn office at a convenient time, even though many times they stay late after their regular hours, just to make it easier for me.

5. Having all of the above and being a great diagnostician – knowing exactly what I need and when - makes Dr. Robert Giusti, and Chris Mavaro my CF doctor and nurse of choice.

I hope I was able to give some of you CFers advice on what important qualities a CF center should have. This was meant to help you realize that there are choices of CF centers and you are not stuck at one place just because you were there your whole life. Each person needs to choose the center that best fits them. These are just five qualities I wrote about, there may be more or you may need only some. Whatever the case may be, as long as your doctor has the important qualities that you need, you are at the right place. Best of luck! ▲

Bracha is 33 and has CF. She and her husband, Yonason, live in Marine Park, Brooklyn, NY, with their two daughters. Bracha is the Editor–in–Chief for a CF newsletter called, "The CF Family Times". To be added to their mailing list, contact Bracha by email at: cffamilytimes@gmail.com or ask your CF center for a copy

Executive Director Position Available for Breathing Room

Breathing Room is a cystic fibrosis (CF) specific Arts and Healing organization (www.thebreathinroom.org) that was founded over 10 years ago. We are an all volunteer, non-profit organization and our keystone project is "Through the Looking Glass: Images of Adults with Cystic Fibrosis". *CF Roundtable* features a Breathing Room image in each issue and we have exhibited at cystic fibrosis conferences since 1996.

- We currently maintain a collection of over 40 photographs and writings, and exhibit the collection at CF conferences and education days throughout the United States.
- The position of Executive Director is a volunteer position and requires a time commitment of 10-20 hours per week.
- We are looking for someone with a strong vision of what the Breathing Room is, the value it brings to the greater cystic fibrosis community and who can carry on the mission of Breathing Room.
- The ideal candidate will have a commitment to the CF community, believe in the concept of Arts and Healing and demonstrate the ability to manage and organize an all-volunteer organization.
- In addition, the person should have experience with fund-raising and be willing to travel throughout the United States.
- Website design interaction, social media skills and professional contacts throughout the cystic fibrosis community are a plus.
- Someone with a personal connection to CF is preferred, but not required.

If you are interested in this position, please send a résumé and letter of interest (e-mail or snail mail) to: michelle@thebreathingroom.org or Michelle Compton, 17499 San Franciscan Dr., Castro Valley, CA 94552

Applications accepted through January 31, 2011.

Pondering Lung Transplants

By Janice Tate

Part One – Eureka!

I never had a desire for a bilateral lung transplant. The biggest reason was that I've been comfortable with my own death for as long as I can remember. I appreciate life, live it to the fullest day by day, but have been prepared to die at a young age. At first I thought it would happen before I was a teenager, then in my 20s or 30s. My life-span kept expanding beyond years I could have ever imagined.

In February 2009, as tune-ups became more challenging, because of antibiotic intolerance and little positive impact, I had a Eureka moment. I thought, "If I had a lung transplant maybe I wouldn't need to deal with *this* trouble any longer." That possibility is what led me to be evaluated for a transplant.

Although I initially entertained the idea of lung transplantation to avoid tune-ups, I began to dream about the full potential that it could offer. What would I do with 3-4 extra hours a day not taking care of my lung disease? What would I do with being able to walk, dance, or run without effort? What would I do with the extra energy and being able to do all the simple daily stuff with minimal effort?

I could take a class to learn cooking basics so my husband, Bob, wouldn't have to make dinner after a long day of work! My dog and I could try agility runs! (I am confident she would be great if only I could do it with her) I could train dogs as a job! The possibilities in my life suddenly seemed endless... I was energized just thinking about the potential!

However I held back from dreaming too much. My husband and I wondered if a transplant center would even consider me as a candidate because Bob also has cystic fibrosis (CF). We were especially concerned about the possibility of the bacteria in Bob's CF- infected lungs infecting my new lungs post-transplant. But the Transplant Center informed us that rather than contracting an infection from Bob, the chances were higher that I would infect my new lungs through my *own* sinus organisms. They would allow me to proceed with the evaluation. My being married to someone with CF was not a blockade for them.

> "'Your no is someone else's yes.' With that simple thought, a flood of peace and joy flowed through me."

We did whatever tests I could at my local CF center. A few months later I stayed a few nights near the transplant center to continue, as an outpatient, the evaluation testing and to learn more about bilateral lung transplants. I was amazed by the intense regimen that pre- and post-transplantation entailed. The people I knew with successful transplants were so grateful for their changed lives that they seemed to minimize the effort required to become listed, remain listed and survive post transplant. Maybe they were like a mother who forgets her labor pains after her child is born. I had no idea how brave a person must be to even accept the challenge of "being listed" for a transplant.

When in the past I mentioned I did not want a transplant, people quickly said, "It's a personal choice." I thought they were referring to philosophical and faith issues. But there are so many tangible issues that need to be considered. Will insurance pay? How will you cover the uninsured expenses? If needed, can you live, temporarily, closer to the transplant center while waiting for new lungs? Can you live near the center at least a month after transplant? Do you have someone to check your vomit for undigested pills? Do you have someone who can drive you to the Emergency Room when necessary? Can your body and mind handle possible reactions to the post-transplant medications? Are you willing to make life changes to avoid germs as much as possible? Those are just a few challenges that came to my mind.

I also was shocked to hear that after all the effort expended and the difficult recovery, the average life expectancy post-lung transplant is *ONLY* five years. I personally know people with CF who had their transplants over ten years ago. Still, there is a high risk of death from an infection or from rejection. Additionally with the suppressed immune system, the risk of skin cancer goes up dramatically. My dreams of post-transplant life included fun in the sun!

I thought it was ironic that statistically speaking, I survived longer *not* being listed for a transplant when I initially qualified for an evaluation. My FEV_1 score first went below thirty percent *over nine years ago*. Even if you tack on the estimated two-year wait for organs with the

five year average life expectancy, that total is only seven years.

I almost wanted to stop the evaluation process after the thorough and realistic description of post-transplant life. But a few things kept me going: my own excitement about the possibilities; believing that God directed me to have the evaluation; and encouragement from an experienced transplant friend. I called her from out of town and tearfully asked her how she possibly handled it. She assured me that post-transplant health care was much less demanding than caring for cystic fibrosis advanced lung disease. So I persevered.

The transplant team had a couple of issues that they wanted resolved before they would determine if I could be a candidate. I have had adverse reactions to eight different antibiotics. Antibiotic use is very important for the transplant and they wanted to make sure I could use them. After testing, an allergist was able to determine that I was not any more likely than the population average to have an allergic reaction to at least three antibiotics on my avoid list.

The transplant center also wanted me to have someone other than Bob as my primary support person. Although his having CF didn't prevent me from being listed, we did not want his health to be compromised while taking care of my needs. Bob's mother, who happens to be a nurse, agreed to make sure that I got the care I needed both while on the list and as a "fresh" transplant outpatient. Now I just had to wait for the transplant team's verdict.

Part two – My Heart's Desire

When I received the call to say I was approved as a candidate for a bilateral lung transplant, I was very excited. I explained to the coordinator that I had been waiting to see if I even had *a choice* before investing a lot of emotional energy into a final decision. Now that I had been approved, I wanted some time to pray and choose. Presuming my wait could be a year or longer, I suggested he put me on the list until I called back within a couple weeks with a definitive answer.

To my surprise, he said, "No." He explained my lung allocation score was too high for me to be wishy-washy about my decision. I mentioned that we had a trip to Israel planned in a few months. I thought maybe I should wait until we got back from the trip to let him know. He said, "I think you're sicker than you think." He explained that one of the numbers from my PFT was quite low and if it got much lower I would no longer be a good candidate. I really appreciated his straightforward honesty. I told him I would call him as soon as I had an answer.

I had been counting on having a couple of weeks to quietly pray and focus on my decision. Suddenly I had a sense of urgency to figure out what I should do. Over the previous seven months — from when the evaluation testing began until I received my approval— I had gathered a lot of information. I had thought about the pros and cons. Though I was thinking of it often, I was waiting to actually *decide* until I was assured I was accepted. I had been wondering how well my personality could handle being in the average two-year holding pattern while listed. The fact that I could probably expect a shorter wait because my lung allocation score was high was a great relief for me.

The realization that I had a limited time with my current lung capacity added pressure to make a quick decision. What if the lungs that fit me happened to become available while I was trying to figure things out, or while I was traveling? It seemed to me that if I wanted to be listed, I needed to go with full commitment of availability as soon as possible.

I presumed once I reached the level where I could no longer get around, I would also no longer qualify for the transplant. If I did not want to be transplanted, I needed to enjoy to the fullest the time left at this level of activity before my ability vanished. Enjoying life to the fullest and making a full commitment to be listed were not compatible for me. I needed to choose one or the other.

Because I trust that God wants what is best for me, I started my analysis by asking the Lord his will for me. My prayer led me to the question, "What do you, Janice, want? What is the desire of your heart?" Well…

…I want to breathe without pain and effort. Ok. That will happen in heaven, or sooner with a transplant.

…I want to get to heaven. Okay. Maybe I needed more time on earth, via a transplant, to be ready for heaven. Or maybe the extra time on earth would delay my ultimate goal. Nah. That doesn't matter. God is in charge. Even if I chose to get a transplant, he could have me die while I'm waiting, if it should be so.

…I want to enjoy the last days I do have not worrying about how far I can go to visit my family or take a little trip. (I would need to be within a certain distance of the transplant center when I received a call that the lungs were available.) Yet, couldn't I put plans of visiting family and taking trips on hold as an investment as I waited for new lungs? Then later I could visit those same places and people with a *spring in my step* after transplant?

…I want Bob to not just accept my decision, but to be glad for it. I already knew he was concerned about getting me sick if he caught a cold. Although the transplant center didn't see Bob's "CF unique" germs infecting me as an issue, it still concerned him.

Continued on page 26

…I want to be free of the burdens of daily health care. Taking care of myself has been my full time job for over 12 years. I was diagnosed at birth so every day of my 46 years of life has included some form of medical care. Transplant would not free me from the burden of daily health care. There would be additional medications to take and, with my history of adverse side affects to various medications, it was not appealing (and even scary!) I would have to have bronchoscopies done on a regular basis and that also was not appealing. Still, did that mean I shouldn't get a transplant? I kept remembering that my friends with successful transplants assured me it was a much, much lighter burden than taking care of CF. They also assured me that everything is easier when you can breathe.

I was like a yo-yo. One minute I'd want the transplant, the next I would not. I didn't know which choice I ultimately wanted. Both being listed and not being listed had their own pros and cons. Again I asked myself, "What is the desire of my heart?" I recalled a few years ago I did some life coaching exercises and my top goal then was "Go to heaven." So I was basically back to square one. Sincerely open, I prayed, "Lord, what do YOU want?"

There was no flash of lightening or mystical voice…instead, a saying came to mind. It had helped me in the past when I wondered if I should be on a committee or not. "Your no is someone else's yes." With that simple thought, a flood of peace and joy flowed through me. I was delighted in the idea that lungs which might have gone to me would go to someone else who didn't feel as ready as I am to move on to Eternal Life.

Independently, Bob had been praying too. He trusted that God would give him the grace to get through whatever choice I made. When I told Bob my decision, he was so shocked. He really thought I was leaning toward being listed. He had been steeling himself up to go forward with the transplant. We prayed together about the decision. It isn't just my journey; it is ours. After our prayer, we felt even more comfortable that it was the path we should take.

When I told the transplant coordinator that I did not want the transplant, he too seemed shocked. Apparently, people sometimes drop out of the evaluation process, but it is very rare that someone who is accepted chooses not to be listed.

A few mornings after my big decision, I unexpectedly woke up crying. It was a reminder to me that although I feel much peace about this decision, it still has a sad side. It is not easy news for people to hear. When Bob and I talked about sharing my decision with our friends and family, he suggested that I should not act like I was dying. A bit puzzled, I assured him I would not stop doing treatments. But he meant that I should be upbeat, as usual, when I shared my choice with people. His advice was just what I needed.

Coincidentally the week the transplant center accepted me, my CF doctor prescribed portable oxygen for me for use outside my home. Making the big decision and having people see an outward sign of my lung disease has taken some adjustment emotionally.

I didn't have time to privately come to terms with the impact of learning that I was "sicker than you think", before letting others know there were changes. They could see a change while I was still trying to grasp it. Overall, I feel like I am back to my usual outlook on life: I do all that I can to take care of myself; and I take each day as it comes. I am awed as the days and weeks and years pile on.

I am grateful for the sense of peace I experienced when I made my decision to turn down the transplant list offer. The vivid memory of my moment of peace will help me through times when I doubt if I made the right decision. It is not an easy decision to make and it is an indescribably personal decision. With great empathy, I pray for the gift of peace for all who have to choose. ▲

Janice is 46 and has CF. She and Bob live in Streamwood, IL.

We are sorry to report that Janice died on August 22, 2010, a few weeks after sending this article to us.

GoodSearch.com Helps Raise Money For USACFA

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

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

Mailbox

It's been a while, but it's never too late to send in my annual donation. I love *CF Roundtable*. I always look forward for the next one. And when I get it, I run with it to my couch and read it from front to back, cover to cover!! I enjoy most seeing pictures of other CFers. I look at them, and realize, that I look like anyone else. I tend to think that when others see me - they see this invisible sign on me that says, "I have CF". But then when I get your newsletter I see others who have CF and they don't look different from a person who doesn't have CF.

Thank you again, for a wonderful newsletter. Wishing everyone a happy and, most importantly, a healthy new year.

Bracha Witonsky
Brooklyn, NY

Haley Wester had CF and was valedictorian of her graduating class at Lakehill Preparatory School in Dallas, Texas, before going on to a successful academic career at Stanford University. She died in 1998. Now the Pan American Student Forum and the National Honor Society at Lakehill are honoring Hayley, and her courageous life with cystic fibrosis, by raising funds for the CF Clinic at the Hospital de Niños in San Jose, Costa Rica. They are joining with Olin Dodson, Executive Director of the Melissa Project for CF in Costa Rica. Dodson's Costa Rican daughter, Melissa, was treated at the Hospital de Niños. The Lakehill students, their sponsor and Dodson hope to be joined by Haley's parents at the presentation ceremony at the hospital in March 2011. For information, contact Joan Mayo at: 214-826-2931, ext. 152 or The Melissa Project at: ododson@gmail.com.

Olin Dodson
Santa Fe, NM

Great job! Thank you.

Melinda Anderson
Lighthouse Point, FL

We love reading your publication. Keep up the great work! It's so informative!

Kathy Hansen
Fenton, MI

Thank you. The family appreciates your informative publication

Maria Brown
Lyndeborough, NH

Information from the Internet...

Compiled By Laura Tillman

This issue brings a potpourri of articles from the Internet

BACTERIA

Association Between Respiratory Tract Methicillin-Resistant *Staphylococcus aureus* and Survival in Cystic Fibrosis. Elliott C. Dasenbrook, MD, MHS; William Checkley, MD, PhD; Christian A. Merlo, MD, MHS; Michael W. Konstan, MD; Noah Lechtzin, MD, MHS; Michael P. Boyle, MD. JAMA. 2010;303(23):2386-2392

This study observed patients with CF who had Methicillin-resistant Staphylococcus aureus (MRSA) detected in their respiratory tract. Results show these patients have worse survival - approximately 1.3 times greater risk of death - compared to CF patients without MRSA.
http://tinyurl.com/2am2hkb OR
http://tinyurl.com/3o7td2e

Mucoid and Nonmucoid *Burkholderia cepacia* Complex Bacteria in Cystic Fibrosis Infections. James E.A. Zlosnik, Paulo S Costa, Rollin Brant, Paul Y.B. Mori, Trevor J. Hird, Monica C. Fraenkel, Pearce G. Wilcox, A. George F. Davidson, and David P Speert. Am. J. Respir. Crit. Care Med. 2010, Aug. 13

Patients infected exclusively with nonmucoid Burkholderia cepacia Complex (BCC) had a more rapid decline in lung function (annual FEV_1 change: -8.51% +/- 2.41) than those infected with mucoid bacteria. The data suggest an inverse correlation between the quantity of mucoid production by BCC bacteria and rate of decline in CF lung function. Certain antibiotics may induce a change in bacterial morphology that enhances their virulence. A simple *in vitro* test of

Continued on page 28

CONVERSATION CORNER

Go Out and Live

By Patti Prince

Just as many of you do, I try to face the unique challenges of cystic fibrosis (CF) with determination and strength. My reason for sharing my story is to offer support to others in similar situations.

I was diagnosed with CF when I was six months old. When I was in high school, my health declined steadily, and I later found out that I needed a bilateral-lung and liver transplant. Soon after, I realized I was pregnant. Although I was advised against it by my doctors, I opted to have the baby. I am blessed that my son Brady is now a healthy and happy four-year-old! I received the bilateral-lung and liver transplant in early 2007 and, though there have been some bumps in the road, I am now happier than ever and able to spend my time with family and friends!

I manage my healthcare while taking care of my son, with a lot of help. Fortunately for me, I have a very supportive and hands-on husband, Nate, who is a true partner. When I'm not feeling great, he will take a personal day from work and stay home to take care of our son. Also, my mom and Nate's parents are great and are always willing to help. When Brady is sick I take extra precautions so that he doesn't infect me, and sometimes, I even wear a mask. We make a game out of it!

Like everyone else, I have difficult moments, but when those happen I draw on Brady and Nate as my strongest motivations. Having a child to fight for has made me stay strong. I don't want Brady to grow up without a mommy, so even when I was the most sick, I did everything I could to fight. And I still do everything that I can to stay healthy post-transplant.

If I could share something with those in the CF community, I would say to those who are considering transplant that, yes, it will be hard and, yes, you have to work. But you may be giving yourself the opportunity to be around for your family and friends. And there is no better gift to give to yourself!

My personal words of wisdom are that the most important thing you can do is keep up with your treatments; they are essential to staying healthy for as long as possible. I would also like to emphasize that you cannot let CF get in the way of your life. We are not human beings living in isolation. Do what you need to do to be healthy, and go out there and live your life!

Patti is 28 and has CF. She lives in New York. She was named a Hero of Hope in 2010.

TILLMAN *continued from page 27*

bacterial mucoidy may be useful in predicting the rate of decline of respiratory function in CF.
http://tinyurl.com/26x5w5k

NEWS RELEASE

ARIKACE™ Demonstrates Sustained Benefit In The Treatment Of Cystic Fibrosis Patients Who Have Pseudomonas Lung Infections

ARIKACE is a form of the antibiotic amikacin, which is enclosed in nanocapsules of lipid called liposomes. This advanced pulmonary liposome technology prolongs the release of amikacin in the lungs while minimizing systemic exposure. The treatment uses biocompatible lipids endogenous to the lung that are formulated into small (0.3 micron), neutral liposomes that enable penetration of the biofilm.

Pulmonary function (FEV_1) increased significantly among patients receiving 560 mg of ARIKACE at the end of treatment. The improvement in lung function was sustained at the end of the 56-day off-treatment period. ARIKACE demonstrated statistically significant reduction in Pseudomonas density, including mucoid strains, which was sustained over the treatment period. ARIKACE was well-tolerated for four cycles of treatment over 12 months, and demonstrated adverse effects that are consistent with those expected in a population of CF patients receiving inhalation medicines.
http://tinyurl.com/24c8l8t

TREATMENTS

Location and Duration of Treatment of Cystic Fibrosis Respiratory Exacerbations do not Affect Outcomes. J Michael Collaco, Deanna M Green, Garry R Cutting, Kathleen M Naughton, and Peter J Mogayzel, Jr. Am. J. Respir. Crit. Care Med. 2010. Published ahead of print on June 25, 2010

Continued on page 31

POETRY CORNER

Hospital Games

By Rachel Thompson

Rollerblading through empty rooms;
no one's looking, it's 8:00 at night.
The hospital lobby's tile floor
Becomes a silent rink.

Gliding around tables
beside a Chick-Fil-A and Burger King
The moon bleaches the tile through tall windows
taunting me.

But I'll continue weaving through pillars
placing pennies in circles on desks and windowsills
just to see if they'll disappear.

I flip the arrow underneath the "Restrooms" sign
it points outdoors now.
But tomorrow it'll be pointing to the toilets again.

I'll skate past an elevator that dings as doors open
to let a ghost out
that might float down the halls
to the transit
and maybe follow me back
to room 504 in the other building
where I'll put the mask back on
and skate down hallways
back to the IV pumps and inhalers
(It's all physical therapy anyways.)

Rachel is 17 and has CF. She lives in Jamestown, NC.

RADLER *continued from page 15*

ing it. I was on a mission, but I was not fearless about it anymore. A lot was riding on this decision, and despite my recent clash with my primary physician, he was still a beloved person in my life, and leaving him was heartbreaking.

I learned a very important lesson in all of this, though. The fear of change does not have to paralyze you. There are always choices. There is always another doctor, another team, another path to follow. Choices may be limited in CF care, but choices do exist. Self advocacy is a key component to finding the right fit. You have to know what is important to you because no one practice will have it all. And with every change there will be things you give up and things you gain. My new doctor is a bit of a risk for me. He is a CF pediatrician who has branched out into the world of adult care. The underlying fear in changing over to him is an obvious one. What business do I, as a 48-year-old woman, have being cared for by a pediatrician? I thought about my allergist and all the good he had done for me despite his having no training in cystic fibrosis. I thought about my Dr. Wonderful and the fact that he, too, was new to CF adult care when he first met me. I mulled it over and over. And in the end, my decision once again boiled down to geography. His practice was, simply, the most convenient for me and my family. So I took the risk, knowing full well that I now had the strength to move on to yet another doctor if I happened to make a poor choice.

Luckily, my first impression was that I liked him very much. He knows CF, and he has helped me regain my health. There is, of course, a stark contrast in personality and approach from my previous CF doctor, and we are both working on the art of compromise in all things health related. The precious thing that I lost in this change was direct accessibility to my doctor. My new doctor's practice is based more on a team approach and he relies heavily on his outstanding nursing staff. It has been a difficult loss for me, but, again, with each thing lost there is something gained. His dedicated, competent nursing team has helped eliminate much of the administrative health burdens that I had previously been shouldering. And even though I speak with him directly only during office visits or the rare urgent phone call, I am confident that any decision made on my behalf comes solely from him. He has passion, he cares about his patients, and he truly wants to see me achieve my personal best. Ironically, he is also a bit of the hope-inspiring sort, and is on a somewhat successful mission to recruit me. I'm trusting in my gut, knowing full well, it has never let me down before. I have had the good fortune in my lifetime of finding two life-changing, caring practitioners, and I will be totally delighted if it comes to pass that three is the charm. ▲

Debra is 48 and has CF. She is a semi-retired CPA. She, her husband, Adrian, and two step-children live in Roselle, IL, with two bichon frise pups. Her contact information is: debraradler@hotmail.com

2010 CFRI CONFERENCE REPORT

Pain and Posture

Presented by Mary Massery, P.T., D.P.T.
Cardiovascular and Pulmonary Physical Therapy
Glenview, IL
Reviewed by Maggie Sheehan

This year's CFRI conference was again a spectacular event. For the past five years I have always enjoyed the speakers and their information, but this was the first year a presentation really hit home for me.

I have had bad posture since I can remember, and I have noticed my back pain getting worse in the last couple of years. Standing for more than twenty minutes gives me a lot of aches and pains in the middle of my back. When I saw in the conference brochure that Mary Massery was speaking I had a glimmer of hope that she might give me some useful information on my bad posture.

Mary Massery is a physical therapist who has worked with many kids with CF for a number of years. She has worked hard to understand how CF affects our posture and alignment. Mary started her talk with explaining how our posture is different from people without CF and different from other chronic illnesses. As she went through the slides, she showed us how people with CF use so much forced pressure from the inside to cough, which gives us our rounded shoulders.

Mary went on to speak about a specific patient she helped who had CF. She talked us through the beginning evaluation through the different exercises she had this patient do, to the end results, which were remarkable. Most exercises had to do with strengthening the back muscles and pulling back the shoulders. Most exercise did not look strenuous and Mary explained once they are learned properly they are very easy to do on one's own time. After six months, this young patient with CF had her shoulders back, her head was held higher and she bore weight evenly on both legs instead of favoring one over the other, as she did before she started physical therapy. Mary also talked about this patient's weight going up and her lung function improved as well.

> "Mary expressed how essential physical therapy is to managing CF."

This talk was like a big light bulb going off for me. I realized this was exactly what I needed to feel a bit better. Not only would I like my pain to go away, and maybe my health improve a bit, I would also like to have a better appearance instead of always looking hunched over. Mary expressed how essential physical therapy is to managing CF. She explained how important it was that it should be something that is talked about regularly with our doctors because it can improve our health.

I had the pleasure of speaking with Mary after her talk and she noticed that I was nodding to all of her points. After this discussion I realized I needed to go home to Chicago and look into getting myself a physical therapist to see how much I can improve my pain and posture. I have not been able to look into physical therapy yet, but plan to do so soon because Mary really spoke to me on the importance of physical therapy as another part of my daily CF care. ▲

Maggie is 22 and has CF. She is a Director of USACFA. Her contact information is on page 2.

IMPORTANT CHANGES

You may have noticed that USACFA and *CF Roundtable* have experienced some changes. There are new officers and board members in our organization. *CF Roundtable* has a different column: "Editor's Notes" rather than "A Word from the President." Also, USACFA has expanded to the point where we have two separate addresses for different purposes. We ask that all correspondence that does not include any money in it be sent to the old PO Box number and that all mail containing money of any kind be sent to the new PO Box.

When sending in a subscription or donation of any amount, send it to: **USACFA, PO BOX 151024, ALEXANDRIA, VA 22315-1024.**

All articles, general inquiries, comments, questions, or praise should be sent to: **USACFA, PO BOX 1618, GRESHAM, OR 97030-0519.**

Strengthening Couples In CF Families

Presented by Damien Wilson, LCSW,
Pulmonary Clinic - CF Care Center
University of Wisconsin Hospital and Clinics
Madison, WI
Reviewed by Laura Tillman

Bold. Provocative. Gutsy. Daring. Not exactly the words that come to mind when discussing a speaker at a CF conference. Yet, that's exactly what Damien Wilson's presentation was. Mr. Wilson's proposal was in direct opposition of the Cystic Fibrosis Foundation's stance on patient interaction. He contends that adults with CF, as well as family members, need the strength and sense of empowerment which only support groups can provide.

Mr. Wilson continued his speech by discussing the aspects of diagnosis of a chronic illness: what the CF Center presents to the family vs. what the family hears at time of diagnosis; the psychosocial stages that the patient and family encounter throughout their journey with CF; the paradox of treatment vs. healing; the limitations of the medical model; and that strengthening and healing happen when the CF Center staff can value individuality, shape a message of hope and belief in a future, incorporate the ideas of the patient/family, and facilitate person-to-person support groups utilizing strict infection control measures. He then went on to explain that the University of Wisconsin Health CF Care Center promotes CF Support Groups and to explore how these groups create an atmosphere of mutual respect, learning, and couple-to-couple learning and why it is so vital that CF Centers develop this type of program.

While Mr. Wilson's message was a vital one, in that the medical community needs to deal with all aspects of the patient, it did not seem geared for the audience at which it was directed but, rather, for health care teams. While it was informative, it did not really address the topic and was disappointing to those who were hoping to gain some insight into how couples can cope with the effects of living with a chronic illness, whether as parents of a child or as committed couples. ▲

Laura is 62 and has CF. She is a Director of USACFA and is the President. Her contact information is on page 2.

TILLMAN *continued from page 28*

Intravenous antibiotic therapy for CF respiratory exacerbations administered in the hospital and in the home was found to be equivalent in terms of long-term FEV_1 change and interval between courses of antibiotics. Optimal duration of therapy (7-10 days) may be shorter than current practice.
http://tinyurl.com/28ytdtq

Tolerance and efficacy of ceftazidime in combination with aztreonam for exacerbations of cystic fibrosis. Prévotat A, Leroy S, Perez T, Wallet F, Wallaert B. Rev Mal Respir. 2010 May;27(5):449-56. Epub 2010 Apr 28.

In chronically P. aeruginosa colonised cystic fibrosis patients, ceftazidime and aztreonam combination (+/-tobramycin, +/-ciprofloxacin) is well tolerated and efficient. This treatment suggests a clinical and functional benefit is possible, even in patients with severe disease.
http://tinyurl.com/22jwgnk

Activity of the new cephalosporin CXA-101 (FR264205) against *Pseudomonas aeruginosa* isolates from chronically infected cystic fibrosis patients. Laura Zamorano, Carlos Juan, Ana Fernández-Olmos, Yigong Ge, Rafael Cantón, Antonio Oliver. Clinical Microbiology and Infection. Article first published online: 7 DEC 2009

Chronic respiratory infection (CRI) caused by *P. aeruginosa* is the main driver of morbidity and mortality in cystic fibrosis (CF) patients. Development of resistance to all available antibiotics is a frequent outcome of these infections. The objective of this study was to evaluate the activity of the new cephalosporin CXA-101 (FR264205) against a collection of 100 isolates obtained from 50 CF patients. CXA-101 showed conserved activity against a high proportion of isolates resistant to each of the antibiotics tested (ceftazidime, cefepime, piperacillin-tazobactam, imipenem, meropenem, levofloxacin and tobramycin). Moreover, CXA-101 retained good activity against multidrug-resistant strains. These results show that major cross-resistance to CXA-101 did not develop during treatment of CF patients with the currently available antipseudomonal agents. Therefore, CXA-101 is envisaged as a valuable alternative for the treatment of CRI caused by *P. aeruginosa* in CF patients.

Continued on page 33

UK Gene Therapy Update

Presented by Eric W. Alton, MD
UK Cystic Fibrosis Gene Therapy Consortium
Imperial College of London
Reviewed by Cynthia Dunafon

Gene therapy works, but how do we make it work well enough?

This year's international speaker at the CFRI conference was Prof. Eric Alton, who directs research on gene therapy at the Imperial College in London. His lab is one of three comprising the UK CF Gene Therapy Consortium established by the Cystic Fibrosis Trust in 2001. In his talk, he described two clinical trials already completed by the Gene Therapy Consortium, and one that will begin in 2011. The overriding question 'How do we make it work well enough?' points to the many technical and regulatory challenges researchers face when moving from a concept that's been proven to work to a substance that works well enough to prevent or even treat the growth of CF lung disease.

A quick look back: going viral

Since the discovery of the CF gene in 1989, researchers have been looking for a way to introduce the corrected CFTR gene into the epithelial cells lining the CF airways. Finding the appropriate vector or gene transfer agent (GTA) to ferry the new gene past the cell walls and into the nucleus has proved difficult, however, since our bodies have a highly developed immune system that tends to reject unfamiliar intruders.

Given the track record of many viruses for lodging in our airways (think of the common cold), researchers initially tried using the adenovirus as a GTA. Unfortunately, the body's immune response kicked in after the first dose, leading to inflammation and essentially eliminating any possibility of repeat doses. Based on current knowledge, any sustained effect in the CF lung requires multiple dosing because each generation of epithelial cells requires the genetic correction - and they have relatively short life spans. The possibility of therapeutic benefit for the CF patient also depends on the efficiency of gene transfer in the nuclei of the cells, which also was wanting in the early adenovirus trials. So, researchers demonstrated that gene transfer was possible, but length of treatment and efficiency at the cellular level remained problematic.

> "Researchers demonstrated that gene transfer was possible, but length of treatment and efficiency at the cellular level remained problematic."

The adeno-associated virus, the next generation GTA, produced less of an immune response in the airways, making it safer for human use. Yet repeat doses again showed little or no gene transfer. In all likelihood, the immune system was still too vigilant. Interestingly however, further research into the inefficiency of the GTA led to the discovery that the receptor sites on the cell walls (where the molecular structure allows particular vectors to enter the cell) were in different locations on the surface of the human cells than they were in the murine epithelial cells studied in the pre-clinical phases of research. In human cells, the receptors were not located on the apical side facing the airways where the drug entered the body, but on the opposite basolateral side. So, while this vector did not turn out to be the "the one" for therapeutic use, the research led to important discoveries in cellular function that impacted how future GTAs were designed.

Plasmids and the new wave:

In his talk, Prof. Alton described the progress he and his colleagues have made in gene therapy using non-viral vectors, such as liposomes, for gene transfer agents. Liposomes are made up of fatty molecules called lipids that can act like a vector by binding to certain protein receptors on cell walls. These GTAs are less toxic and unlikely to set off an immune response in the airways, which opens up the possibility of repeat dosing. While liposomes themselves are not very efficient vectors, they have the potential to allow more efficient gene transfer inside the cell thanks to the size of the DNA strand to which they can be attached. With viral vectors, the size of the virus limits the amount of DNA code it could ferry into the cell. In fact, the corrected CFTR gene has to be stripped down in order to fit! But liposomes can surround a larger molecule capable of carrying both the corrected gene and a stronger promoter code to enhance the DNA transfer once it enters the nucleus of the CF epithelial cell.

In a safety trial called "Wave 1", Prof. Alton and his colleagues used a plasmid molecule surrounded with lipids, called pGM169, to carry the

requisite DNA into the cells. A plasmid is a circular strand of DNA (often taken from bacteria) capable of transferring genetic information to another organism outside the normal process of replication. In other words, replication via a plasmid allows a CF epithelial cell to express the corrected CFTR gene right away, before it divides and creates new cells. Data from this trial demonstrated that a 25% improvement in the basic defect of the CF lung was possible – at least temporarily.

The following trial, dubbed the "Run-In Study" was a longitudinal study involving ~150 CF patients over a two-year period. Trial participants inhaled a single dose of the same gene therapy drug used in Wave 1. The results were encouraging but inconsistent, meaning that some participants showed significant increase in chloride transport, others saw marginal increase, and a few had no increase at all.

With dry humor and echoes of Job-like perseverance, Prof. Alton described some of the complexities that can bollix the movement of scientific investigation from bench science to clinical trials. For instance, the powdered form of the GTA for the Wave 1 study needed to be kept at a lower temperature than the glass vials and rubber stoppers were engineered to withstand. And the plot thickened when it was discovered that the commercial process of cleaning the new and improved vials and stoppers led to impurities in the GTA. In the Run-in Study, regulators demanded a new device for mixing the lipid and DNA molecules. Ordinary syringes just would not do. Throughout the research process, scientists face a Kafka-esque maze of reporting and regulatory approval – a different kind of inefficiency that is hardly unique to the UK system.

Obviously, researchers would like to see more consistent results in future trials. But the range of responses in the "Run-In Study" raises other interesting questions. How much change in chloride transport will lead to therapeutic benefit? For instance, a small increase over time may help prevent lung deterioration, which could be helpful in the early stages of CF; but would a larger increase in chloride transport actually treat existing lung damage? According to Prof. Alton, there may not be a linear relationship between dosage and therapeutic effect. Researchers must ascertain what endpoints are relevant and how they correlate with CFTR function. The next steps for the UK CF Gene Therapy Consortium will include a multi-dose trial with pGM169, slated to start in the spring of 2011, and an improved GTA for future trials dubbed "Wave 2" and already in the works at their labs.

References:

I supplemented Prof. Alton's material with background information to help clarify the issues he presented, and am responsible for any errors that appear here. For more information, please visit the UK Gene Therapy Consortium website (http://www.cfgenetherapy.org.uk/Default.htm), Eric Alton's published papers (many are available on PubMed), and Wikipedia for useful descriptions of basic cell biology (including "plasmid", "liposome" and "gene transfer"). ▲

Cynthia is 46 and has CF. She is a Director of USACFA and is the Vice President. Her contact information is on page 2.

TILLMAN *continued from page 31*

http://tinyurl.com/2djhwep

LUNG TRANSPLANTATION

Survival of Burkholderia cepacia sepsis following lung transplantation in recipients with cystic fibrosis. E.F. Nash, A. Coonar, R. Kremer, E. Tullis, M. Hutcheon, L.G. Singer, S. Keshavjee, C. Chaparro. Transplant Infectious Disease. Published Online: 11 Jun 2010

Cystic fibrosis (CF) lung transplant recipients infected with *Burkholderia cenocepacia* have a worse survival rate after lung transplantation than those who are not infected with this organism. The decreased survival is predominantly due to recurrent *B. cenocepacia* infection, with the majority of affected recipients succumbing within 3 months after transplant. *B. cepacia* complex (BCC) sepsis is one of the defining criteria for cepacia syndrome, an almost universally fatal necrotizing pneumonic illness. We report 2 CF patients who were long-term survivors of *B. cenocepacia* sepsis after lung transplantation. The aim of this report is to demonstrate that, although survival of *B. cenocepacia* sepsis after lung transplantation is extremely uncommon, with aggressive multidisciplinary management, long-term survival remains a realistic objective.

http://tinyurl.com/24gsyh8

Lung transplantation in patients with cystic fibrosis and Mycobacterium abscessus infection. Marita Gilljam, Henrik Scherstén, Martin Silverborn, Bodil Jönsson, Annika Ericsson Hollsing.Journal of

Continued on page 34

TILLMAN *continued from page 33*

Cystic Fibrosis. Volume 9, Issue 4, Pages 272-276 (July 2010)

Lung transplantation in patients with M *abscessus* lung infection is feasible but may involve severe complications.
http://tinyurl.com/2ufztyt

GENDER

Gender differences in the Scandinavian cystic fibrosis population. Hanne Vebert Olesen MD, Tacjana Pressler MD, DMSci, Lena Hjelte MD, PhD, Lena Mared

MD, Anders Lindblad MD, PhD, Per Kristian Knudsen MD, Birger N. Lærum MD, PhD, Marie Johannesson MD, PhD. Article first published online: 29 JUL 2010

No gender difference in key clinical parameters in the CF population was found. However, the study showed a higher risk of *Pseudomonas* and *Burkholderia* infection among the female patients. Additionally, it was found that female patients require more intensified treatment regarding antibiotics, macrolides, steroids and days of hospitalization, indicating a true female disadvantage even with modern aggressive treatment. The finding of more males than females in the adult population suggesting a male advantage, warrants a mortality study.
http://tinyurl.com/29m5drc ▲

Laura is 62 and has CF. She is a Director of USACFA and is the President. Her contact information is on page 2.

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:

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Please include your name and contact information.

EISENMAN *continued from page 16*

was not sure I wanted to go through testing another acupuncturist. I didn't want to take herbs that might cause rejection or interfere with my levels of Western medication. So, I demurred. Finally, my CF friend was in town visiting and she had just seen Jackie and she told me I had better go. Whenever she came to NYC, she visited her friends but most important was for her to see Jackie. I was getting sinus infections again and feeling mediocre. So, I went. I felt I had nothing to lose and maybe something to gain.

Once I met with Jackie and she treated me, I was so mad at myself for waiting so long to see her. I understood why my friend had raved about her. She has changed my life as well. Jackie completely gets CF from a Western view and from a Chinese Medicine reference. She also treats me as a whole person. She tells me she is going to connect my heart with my kidney and spleen and increase the flow to my lungs by strengthening the mother-daughter bond—what? But whatever she does, it helps me. My HgbA1c has been much lower since I started seeing her. My sinuses have been better too. She understood that I did not want to take any herbs and my reasons. I feel her goals and my goals are the same, to keep me well and extend my life and fill in the gaps of Western medicine when possible. Even though I do not always understand what she is talking about, when she needles me, the end result is, I feel better and feel more in control of my health. She also has a cadre of wonderful massage therapists who work there with her. At some point during a visit, usually after her needles are out, I get a massage to help the acupuncture do its work. The whole experience has given me hope.

I still see my refelxologist in Chinatown every so often, especially when Jackie is away. It actually helps to elongate Jackie's treatments.

What I love about her is that Jackie encourages involvement from her patients in their own care and fosters their learning about their bodies. There is also mutual respect. And I trust her implicitly. I know that I can always come to her with a problem about my health and she will gladly take it upon herself to help me solve it.

Finding Jackie was not easy. I did not know what I really needed or wanted from an acupuncturist or an alternative health provider but now that I have Jackie, I know exactly what it is. It is about having a caring person who will listen, learn and teach. Not dictate what is best for you but work together and keep an open dialogue. I am just so grateful. ▲

Andrea is 45 and has CF. She is a Director of USACFA and is the Executive Editor/Webmaster. Her contact information is on page 2.

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