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

Hope Has Arrived: FDA Approves New Drug

By Beth Sufian, J.D.

On February 22, 2010, the U.S. Food and Drug Administration (FDA) approved Cayston® (Aztreonam for inhalation solution) as an inhaled antibiotic treatment for people with cystic fibrosis with Pseudomonas aeruginosa. Cayston is the first CF-specific drug to be approved by the FDA in 10 years.

The CF community should be grateful for the efforts of Gilead Sciences, Inc., the company that manufactures Cayston. In addition, we should appreciate the CF Foundation's support of research studies for Cayston at each stage of development, and advocacy for its approval. Without Gilead and the CF Foundation's dedication and persistence, we would not have access to the drug. This article attempts to educate *CF Roundtable* readers on the long road to FDA approval for Cayston. The opinions in this article are solely those of its author.

In September 2008, I was boarding a plane when my cell phone rang, "The FDA denied the drug," a good friend said. "You mean approved the drug?" I asked. "No, denied." Suddenly, the flight attendant was telling me to turn off my phone. The plane took off and tears started streaming down my face. I knew that many people with CF were anxiously awaiting approval of Cayston and needed it in their fight against CF. That day was the beginning of an 18-month struggle by hundreds of people to make sure the drug was approved by the FDA.

Gilead filed an appeal asking the FDA to reconsider the denial. The FDA denial had reasoned that the CF community had TOBI® and so did not have an "unmet medical need" necessitating a new inhaled antibiotic. When the appeal failed, a request for a hearing before an FDA Advisory Committee was requested. The hearing would allow an FDA Advisory Committee, made up of physicians and researchers, to hear evidence from Gilead and the FDA. The Committee would then decide whether to recommend that the FDA approve the drug. If the hearing was unsuccessful there would need to be new research studies which would take 2-3 years.

The FDA Advisory Committee hearing took place on December 10, 2009, in Maryland. The main scientist who developed the drug, Dr. Bruce Montgomery, passionately explained the research that supported approval of the drug. Dr. Frank Accurso, the director of the CF Center in Denver, Colorado, gave an excellent overview of CF, the treatments available and the desperate need patients had for another inhaled antibiotic. Dr. Quitner from Florida answered questions about how the research data was compiled. Dr. Wolfson, a physician and researcher, did an incredible job explaining the research data. I had the chance to speak to him after the

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EDITOR'S NOTES

Welcome to our spring edition of *CF Roundtable*. With the new season comes renewal, warmer weather, new green leaves, and blossoms… and for those unfortunate people, allergies. Spring allows all of us to get outside more and enjoy nature with longer walks, gardening, or whatever we don't get to do during the colder months. I welcome this.

We have some great articles for you to enjoy. First up is our cover story, written by **Beth Sufian,** regarding exciting news of a hopeful drug. Cayston®, inhaled astreonam, was recently approved by the FDA to treat CF and, specifically, Pseudomonas aerugenosa (PA).

Inside this issue, from our columnists we have: *Spirit Medicine* with **Isa Stenzel Byrnes** writing about touch and the loss of this important tactile bond with others in the CF community, due to cross-infection concerns. She writes about her frustration and other outlets for the "gift of touch." In her *Wellness* column, **Julie Desch, MD,** reflects on the saying, "Wherever You Go, There you Are", by Jon Kabat-Zinn. Through his Mindfulness Based Stress Reduction (MBSR), she learned to reduce stress and to better care for her body and soul by creating a meditation practice. In keeping with our focus topic of travel, **Kathy Russell** writes in *Speeding Past 50* about how, when she and her husband, Paul, travel, planning ahead is key to a successful trip. In *A Deep Breath In,* **Debbie Ajini** writes about how traveling while being on oxygen full-time can complicate a vacation. But she shares her views on making a trip rejuvenating and fun in her current situation. **Laura Tillman** shares her *Information From The Internet* on new medications and research in the CF world. And, in *Ask the Attorney,* **Beth Sufian** writes about what happens if there is an overpayment from Social Security, one's responsibility and the actions one must take.

The focus topic of this issue is: "Traveling For Work or Pleasure With CF." We have an article from **Walter Van Praag** who writes about his tips for traveling the globe and the importance of travel insurance and **Andrea Eisenman** who writes about wearing a mask to filter the air during air travel.

In Conversation Corner, **Bracha Witonsky** shares her comical story on what not to do when you have pain in your ear. In *Voices From The Roundtable* we have articles by **Darleen Boynton** regarding young adult CF anxiety, **Marcus Harris** on important financial decisions facing adults with CF, and **Sue Connors** who shares good advice on maneuvering the Medicare Part D maze.

Check out the *Milestones* on page 3 and consider submitting your own soon. On page 11, you can read how Genentech is trying to make their medication more affordable to patients. As always, please consider writing an article on one of our upcoming focus topics (on page 3) or submit something on what interests you regarding your life with CF.

Until the next time, stay happy and healthy.

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

Ed Fleischman
Plainview, NY
68 on December 24, 2009

Lawrence V. Lafary
Riverton, IL
70 on December 5, 2009

Kathy Russell
Gresham, OR
66 on April 17, 2010

Wedding

Lucille & Robert Kinsel
Canton, IL
50 years on November 8, 2009

Kathy & Paul Russell
Gresham, OR
45 years on March 27, 2010

Susan & Mark Vitale
Kirtland, OH
40 years on August 2, 2009

Transplant

Paul Albert, 50
Catasauqua, PA
Bilateral lungs
17 years on February 10, 2010

Greg Briggs, 56
Jacksonville, FL
Bilateral lungs
13 years on April 30, 2010

Andrea Eisenman, 45
New York, NY
Bilateral lungs
10 years on April 25, 2010

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**

Spring (current) 2010: Traveling For Work or Pleasure With CF.

Summer (August) 2010: Becoming A Parent With CF. (Submissions due June 15, 2010) Have you become a parent or do you want to? Have you learned any tips that could help others? Please tell our readers of your experiences.

Autumn (November) 2010: Choosing The Right Caregiver. (Submissions due September 15, 2010) How do you decide what caregiver to use? Would you move to another location to be seen by a specific caregiver? Are there any tips you can share on how to avoid any pitfalls when choosing a caregiver?

Winter (February) 2011: Sleep Or The Lack Of It. (Submissions due December 15, 2010)

ASK THE ATTORNEY

Questions from Readers

By Beth Sufian, Esq.

The following column is based on questions asked by a number of readers in the past three months concerning Social Security overpayments. Questions asked by readers are never disclosed without the agreement of the reader and information will never be published that would allow anyone to identify the reader who asked the question. Nothing in this column is meant to be legal advice about your specific situation. Social Security overpayments are often complicated and there are very few attorneys who know anything about Social Security overpayments. If you have additional questions please contact the CF Legal Information Hotline at 1-800-622-0385. The Hotline provides free and confidential legal information to people with CF, their families and their CF Center care teams. The Hotline is sponsored through a grant from the CF Foundation. The Hotline can also be reached by e-mail at CFlegal@cff.org.

I have received an overpayment notice from Social Security that they have overpaid me and that I must pay them back $30,000. What can I do?

BETH SUFIAN

1. General information on overpayment

Social Security is aggressively pursuing overpayment cases. An overpayment occurs when a person receiving Social Security benefits has been paid more in benefits than the person should have received under Social Security rules. The amount of the overpayment is the difference between the amount a person received and the amount that was actually due. An overpayment can be caused by many things. Individuals who receive Social Security Disability benefits can work part time and still receive benefits. However, the individual cannot make more than a certain amount of money from part-time work. If an SSDI recipient works and makes more than the allowable amount, SSA eventually determines that the person has an overpayment and sends notice that the person must repay a certain amount. Social Security can send the overpayment notice at any time. Social Security may take a while to discover the overpayment. There is no time limit within which Social Security must notify a person of the overpayment.

IMPORTANT: If you have been receiving benefits and then return to full time work and stop receiving benefits, make sure you update Social Security when your address changes. In the event Social Security determines you have an overpayment from the time you were receiving benefits, then having the correct address will allow them to notify you of the overpayment. It will also allow you to either appeal the overpayment or request a waiver of the overpayment. If you never receive the notice of the overpayment, Social Security may start to garnish your wages from your current job. While it is possible to fight the overpayment at that time, it is more difficult to have the overpayment overturned.

For example, in 2010 the amount a person on SSDI benefit is allowed to make from part-time work is $1,000 per month. If a person receives SSDI benefits and makes $1,200 in one month from work activity, then they may have an overpayment situation and will not be eligible for benefits after that month. If Social Security discovers the overpayment 12 months later, then the SSDI recipient has been overpaid for 12 months and will owe all benefits paid in that 12 months. The SSDI recipient is liable for not only the one month the person made $200 over the limit; the person will be liable for all the money paid after that month.

The only time a person can make more money than the amount that is allowable monthly is during their trial work period. Each person who starts receiving SSDI benefits has 9 months in which they are allowed to make more than the allowable amount. But once the 9 months has been satisfied, if the person goes over the allowable amount by even $1, then benefits should stop. The SSDI recipient has the duty to notify Social Security of earnings over the allowable amount. It is best to do so in writing. If a person continues to receive SSDI benefits and knows that their month-

ly income from work activity is over the allowable amount, some advocates suggest making a copy of the check and sending it back to Social Security. Social Security representatives have access to the IRS data base. This means that if income from work is reported to the IRS, Social Security will be able to access that information.

Eventually Social Security will find out if a person is making more than the allowable amount from work activity. Once the information is checked, often during a standard review of a person's file, then the person will have an overpayment and owe Social Security money. In some cases if a person is still receiving benefits, the benefits will stop until the overpayment is paid back. If a person is not receiving benefits anymore, Social Security can garnish up to 25% of wages.

2. Different rules for SSI

Individuals who receive SSI benefits have different restrictions on their ability to make money from work activity or to receive income from any sources. Individuals who receive SSI need to make sure that the SSI income rules are followed. The following situations may result in an overpayment for an SSI recipient, if Social Security is not notified of a change in income or living situation:

1. Living situation has changed which may reduce the amount of SSI benefits a person should receive.

2. Marital status has changed which may reduce the amount of SSI benefits a person receives from Social Security. For example, if an SSI recipient marries and their new spouse has income from work over the allowable amount then the person receiving SSI benefits will no longer be eligible for benefits.

3. More resources than the allowable limit. For example, an SSI recipient receives a $3,000 gift from a relative. SSI recipients who are single can have only $2,000 in assets. Receipt of $3,000 would put the SSI recipient over the income limit.

3. If there is an overpayment

Social Security will send a notice explaining the overpayment and asking for a full refund within 30 days. If a person is currently getting checks and does not make a full refund, the notice will either propose to withhold the overpayment at the rate of 10 percent of total income; state the month the proposed withholding of benefits will start; fully explain appeal rights; explain how a person can ask Social Security to have the overpayment reviewed and waived; and explain how the decision can be appealed. Again, it is very important to keep Social Security aware of your address so that you can receive an overpayment notice, if necessary.

> *If a person believes he was not overpaid, he may request a reconsideration. The request must be in writing.*

4. What can a person do if you receive an "Overpayment Notice"?

If a person believes he was not overpaid, he may request a reconsideration. The request must be in writing.

IMPORTANT: If the appeal is filed within 10 days of the date on the notice, any payment the person currently receives will continue until Social Security makes a decision, if receiving SSI benefits. If a person believes that he may have been overpaid, but feels that it was not his fault the person can:

1. Ask for a waiver of the overpayment.

2. Ask for and complete form SSA-632 (Request for Waiver). A person can ask for a waiver at any time.

If Social Security grants a waiver, the person will not have to repay the overpayment. In order to be eligible for a waiver, the person has to show that the overpayment was not the person's fault. For example, the person had notified Social Security of his income from work activity but had been told he could still receive benefits. It will be important to have a copy of the letter that was sent to Social Security, as proof that the person notified Social Security of the change in income.

Another way to obtain a waiver is to show the overpayment cannot be paid back because the money is needed to meet ordinary living expenses. A person may have to submit bills to show that monthly expenses use up all of monthly income and that it would be a hardship to repay the overpayment.

A person may ask to see their file to see the information Social Security used in figuring the overpayment. A person may also ask Social Security to explain the reason for the overpayment. Most important - do not ignore an overpayment notice. It will be much easier to act quickly and resolve the overpayment than to ignore it and have future wages garnished. Overpayment is a complex area of the law. Make sure you understand your options. ▲

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

SPIRIT MEDICINE

Touch As a Spiritual Gift

By Isabel Stenzel Byrnes

I'm in the Emergency Room, watching my twin sister, Ana, writhe in a feverish pain. I stand over her gurney, massaging her legs. I come home and my basset hound bullets in from the yard, her cacophony of yelps bounces off the walls. When I reach down to this wriggling sausage and stroke her head, she stops barking. I kneel down to sit and start to rub her torso; she calms down completely. I sit on the couch with my husband. I tell him I'm worried about Ana's infection, and wonder how much time she has, or I have. He reaches out to put his arm around me, we lean our heads together and embrace.

These ordinary life moments are made precious by a simple healing gift: the gift of touch. This Spirit Medicine focuses on the power of our touch to heal our spirits. Whether it's a gentle arm on the shoulder, a pat on the back, or a tight embrace, any form of touch can be a spiritual act that triggers a connection between people.

Affection is a natural need. We humans have been hard-wired to be receptive to touch, for social bonding. Our lives actually depend on it. In classic developmental research, newborns in the nursery that were not picked up, caressed or hugged, died of what psychologist John Bowlby called "anaclitic depression". Children of depressed mothers, who are deprived of nurturing touch, suffered from failure to thrive.

Research has shown that physical touch in adults also has tremendous health benefits. A brief hug and ten minutes of handholding with a romantic partner greatly reduce the harmful physical effects of stress. Blood pressure and heart rate are higher in people who do not engage in regular touch compared to people who hug others regularly. A recent article in the *New York Times* reported that the best basketball teams (notably the Boston Celtics and Los Angeles Lakers) had players who touched each other – with high-fives, fist-bumps, hugs, and pats – more than the bottom tier teams. Touch is a powerful form of communication that helps to uplift and inspire teammates.

It's no wonder that family therapist Virginia Satir promoted affection for healthy marriages. She said, "We need four hugs a day for survival. We need eight hugs a day for maintenance. We need 12 hugs a day for growth." Touch between two people who care about each other is reassuring and affirming. It's as if a transfusion of energy is shared. When one is ill or distressed, this touch has even more power. But it seems the CF community is touch-deprived. When one of my CF friends is having a really hard time, I yearn to give her a hug or to hold her hand. It is a tragedy that I am unable to physically show affection to my CF friends, because of cross-infection concerns. I feel like I'm risking my life just by patting my CF friend's shoulder. When one of my longtime CF friends died a few years ago, I was devastated to realize that the only time I ever touched her was when I touched her casket. Not touching to me seems completely unnatural.

> *"It is a tragedy that I am unable to physically show affection to my CF friends, because of cross-infection concerns."*

ISA STENZEL BYRNES SNUGGLES WITH RUPIE.

I was born with an inclination for affection. Perhaps this trait emerged because I shared the womb with my twin sister. My silent childhood movies often showed me going up to my sister to give her a kiss (she never reciprocated!). As an adult, there is still something primitive, pure, even safe when I put my arm around my sister, when I "booch her up" in jest, or

when we hug. Yet, we grew up in a family culture where hugging and touching were not practiced. When I tried to cuddle with my mother, she would say, "Ammattare!", the Japanese word for overly touchy or needy. When I was a kid, I flew to Japan and met my Japanese uncle for the first time at the airport. I approached him to give him a hug and he pushed me away, saying, "We don't do that here." Thankfully, growing up in American culture, I found friends who modeled to me that it was okay to demonstrate care and love through strong embraces or an arm around the shoulder. These physical acts of affection made me feel more bonded and trustful of these friends. I even have a friend who annoys me regularly, but he gives the best powerful, long bear hugs. Suddenly, I forgive him and love him nonetheless.

At home, though, I grew up doing chest percussion therapy (CPT). CPT always reminded me of the Christian practice of "the laying on of hands", used by Jesus to heal the sick. Even if CPT was a harsh, slapping ritual in an uncomfortable position, it was still healing touch from my parents, sister and, later, my husband because we were all fighting this disease together. With each pat, it's as if the nerves would fire on my skin, sending messages to my brain of an elemental bond. This bond fed my spirit, which helped to heal my body and give me the drive to keep fighting. (Now, all of my CF friends use the mechanical chest vest. I can't help but wonder if this device has kept people with CF from experiencing this healing power of touch.)

Truthfully, though, touch is a touchy subject. In our modern society, touch can have a negative connotation that triggers thoughts of harassment, molestation, hedonism, lewdness or lust. Two men greeting each other with a kiss on the cheek is perfectly normal in some cultures but not in America. In the CF world, touch can mean germ-spreading, or an uninvited intrusion of one's physical space. Sometimes touch doesn't feel safe. When I was in the hospital as a teenager, I often had a respiratory therapist who would place one of his hands on my rear end while his other hand percussed my back. He gave me the creeps. I felt so uncomfortable; I'd scoot up in the bed to try to move his warm, moist hand up my torso, to my waist or ribcage. I was too passive to say anything but just cringed each time he was assigned to me for therapy. The bottom line is that the wrong touch can damage the spirit. That's because touch makes people vulnerable. Touch mixed with attraction becomes sexuality; another wonderful but complicated facet of being human. Sexuality has the potential to confuse, to make unequal, to damage. But sexuality also has the power to invite physical intimacy that takes us to another level of consciousness, even spiritually. Therefore, touch takes courage. Touch requires consent and trust. That's where communication comes in.

Realistically, some people just don't have the luxury of having someone close to them who might offer affection. And others really don't feel comfortable having anyone touch them. There are creative substitutes for the loving touch of another person. Harnessing one's sensuality can also help soothe the spirit. By sensuality, I mean awakening the senses – sight, sound, taste, smell and, especially, touch – to compensate for any physical or emotional distress one may be feeling. There are a million ways to soothe one's mind and soul visually, musically, or with good foods and scents. But how does a person who is alone use touch therapeutically? Some examples include a self-hug, a self-massage or soaking in warm water. Touch is about stimulating the nerves on your skin to relay the message, "This feels good. I'm here, I'm alive. I'm okay."

Here's another example: as I write this, I'm bundled up in a plush pink quilt. I confess that I have a quilt fetish. When I was eight years old and lived in Japan, my mother bought me a thin quilt made of 100% gauze cotton. It was the most billowy soft blanket I've ever touched. Whenever I had a stomach ache, I'd ball that "quiltie" up, lift up my shirt and rub it against my belly. When I had a fever, or chest pain, I'd curl up in it, take the corners and rub it against my face, and for a moment escape into bliss. I used that blanket for years, until shreds caught in my toes at night. I always asked for a replacement, and to this day I sleep with several new generation "quilties".

My spirit also finds solace by cuddling with my warm, soft basset hound, Rupie. Her velvety ears and wrinkled chin are perfect for stroking. The way she sleeps in a ball is made for hugging. Rupie loves to nestle against my chest and moan with bliss. I have a feeling that when Rupie is snug against me, she feels like she merges with me, as if she can't tell she's a dog and I'm a human. Maybe that's the powerful lesson of touch. The intimacy of touch – among pets and people – reminds us that there is a spiritual force much bigger than our own finite separate bodies; and this force merges when physical contact is made. That is why a hug feels so good.

I hope these words "touch" you in some way. May you give yourself a good dose of touch medicine for your spirit. <<HUGS>>!▲

Isa is 38 and has CF. She and her husband, Andrew, (and Rupie) live in Redwood City, CA. She invites you to keep in "touch" with her, regarding Spirit Medicine at: <thepoweroftwomovie@gmail.com>.

SPEEDING PAST 50...
Planning Can Improve Travel

By Kathy Russell

As the weather warms up and the flowers begin to bloom, minds turn to travel. It is such a joy to go places in nice weather and to see all of the beautiful trees and flowers. I love spring. It is a sense of new awakening and it means that I have survived another winter. For those of us who have CF, surviving winter can be difficult. So it always seems to be a victory to live to see another spring.

Most of the traveling that I do now is by automobile. I find that it is much easier to take shorter, driving trips than it is to take longer trips by air or even by train. There is so much "stuff" to deal with, when traveling with CF. The old days of traveling with only one carry-on bag each are just a memory.

When we (the "we" is my husband, Paul, and I) were young we could decide to go some place and just pick up and go. We might decide to take an after-work (we both worked evenings and got off at 11 pm) trip to Reno, just for fun. Since we lived in Portland, Oregon, we could hop on a plane and be in Reno in a short time. We'd play all night and, after breakfast, we'd fly home. Then we would sleep for a few hours and go to work. Oh, to be young again. There is no way we could do that now.

Nowadays, a trip like that would take planning and many more hours away from home. Today one must go through security checks and is looked at as a "risk", when flying without luggage. Of course, there is no trip that I take without luggage, now. If I am going to be gone for a day I must have my oxygen concentrator, nebulizers and compressor, WaterPik for sinus irrigations, and my meds. If I am going to be gone for a longer time, then I have to add The Vest®, and other things to keep me operating correctly.

Just a side note here: when flying with my oxygen concentrator, I must have a letter from my doctor that explains my oxygen use, dosage, ability to get around without O_2 and any other pertinent information. Of course, it goes without saying that the concentrator that you take on a flight must be FAA approved. There are several concentrators that are approved. Check with your O_2 provider for more information.

> *"A large part of successful travel is good planning."*

KATHY RUSSELL

Speaking of meds, it is important that we carry a list of all of our meds and treatments. We should keep this with us, at all times, not just when traveling. On my computer, I have made a list of my meds, the dosage amounts, the frequency of doses, and any other information that is pertinent. I printed it out and keep it with my Medicare, Medic Alert and insurance cards, in my wallet. That way, all of that information is convenient for me to find. When I go to a physician's office, I can just give them the list and I don't have to try to remember all of my meds and their dosages in order to fill out the required HIPAA papers. Such a list makes it easier for us when we must see a new health-care provider, too. Everything is there, clear and succinct. I don't know about you, but I certainly have trouble remembering everything when I am feeling ill.

Some of my medicines need to be kept at particular temperatures. If we are traveling by automobile, this isn't much of a problem. We keep a cooler in the trunk and my meds go in there. If we are flying, then I must pack my meds with something to keep them cool. Usually, I put my Pulmozyme® packet in with an ice pack and wrap them with clothes or a towel. I never have had problems with my meds getting too warm (or too cold).

If we are flying, I make sure that all of my medicines are properly labeled and all together, so that they are easy for the TSA agents to check. Planning ahead can avoid upsets at the security checkpoint.

Another hassle when flying is the limits on liquids and gels that the

TSA has in force. No containers of liquids or gels over 3.4 ounces are allowed. This means that shampoo and toothpaste have to be in small sizes. Also, all of the liquids and gels have to be put in a 1-quart plastic bag that is placed in the bin for easy examination. The exception to this rule is prescription medications. They must be labeled and should all be together for easy inspection.

While we are talking about TSA rules, I must mention the bother of having to take off one's shoes before going through the magnetometer. I refuse to walk either barefooted or in my stocking feet on a floor where thousands of people have walked. I carry a pair of slipper-socks in the outside pocket of my carryon bag. I remove my shoes, don the slipper-socks and go through. Once I get to the other side, I remove the slipper-socks and put my shoes on. The slipper-socks go into a plastic bag and back into the pocket on my carryon bag. I sometimes get some funny looks, but what do I care? My feet and socks didn't get dirty and I'm an old lady and I can be odd.

A large part of successful travel is good planning. We try to travel at non-peak times. In other words, we try to travel when planes aren't packed or when the highways aren't jammed. That way, we avoid crowds at our destination points. We don't have to stand in lines of people, who may be coughing, when we want to go to a tourist attraction. Another part of planning for travel is having trip cancellation insurance. This is very important when taking a flight or cruise. Some of the policies are not too expensive and, if you happen to get sick, they can save you a lot of money.

Planning where you travel is important, too. We do not go places that are notorious for harboring organisms that might be harmful for me. For instance, I have avoided parts of India, Africa and South America. There also are places in the South Pacific that we have chosen not to visit. I stay away from the hotter and more humid parts of the USA during the summer. I find that the climate of the Pacific Northwest suits me just fine. I like our lower relative humidity and the usually cooler summers (although we hit temps over 100 degrees on several days last year.) We complain when our temperature is over 85°F and the humidity gets up to 40% in the summer. We are so spoiled.

For the times when we either must or want to fly someplace, we need to be as safe as we can be. One thing that can help is to wear a mask. There are many types of masks available on the market. (See article by Andrea Eisenman) Be sure to check with your physician about what type of mask will best suit your needs.

Before you decide that traveling is just too much work, remember that one goal of travel is to get out of one's rut. Whether we travel for work-related things, special occasions (family or other types), or just to get away, it really is worth the time and trouble. Much like a new coat of paint to brighten our walls, travel gives us fresh surroundings and new perspectives. I've heard that "a change is as good as a rest", but I'll take "a rest" any day. It seems that I always am happy to get back to my familiar surroundings, no matter how much I liked my trip; but, I look at those surroundings with a new appreciation. So, maybe, an occasional trip can help us to be more satisfied with who we are and where we are.

Stay healthy and happy. ▲

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

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.

FOCUS TOPIC

TRAVELING FOR WORK OR PLEASURE WITH CF

Coughing the Distance

By Walter van Praag

WALTER VAN PRAAG

As a person with cystic fibrosis (CF) you have special overseas travel challenges. Like everything in this world we need to meet them head-on and with optimism. It all starts with a spark, a plan and perseverance. Each challenge seems like a major obstacle when you come across it, but in reality this is not the case! Many can be overcome without too much trouble.

Getting travel insurance for instance: the trick to filling in an application is to fill in applications with five different companies! When the form asks you if you have been refused travel insurance for this trip you can truly tick "NO" on all five forms. You'll still need a letter from your doctor and all the other usual formalities, but in the end you'll probably get a few insurance offers to choose from for your trip. In most cases, however, your pre-existing condition will not be covered by any insurance on your holiday overseas.

Alternatively you can do as I do – apply for a premium credit card, one that includes travel insurance. As it is an added feature of the card, it doesn't ask you any health-related questions. Although pre-existing conditions may still be excluded in the small print, using travel insurance offered by your credit card may be cheaper than buying a separate travel insurance policy. If you don't have the income required to get a Platinum Amex, for example, see if you can find a friend or relative willing to issue you a supplementary card. It is worth the annual fee, especially if you add up the other benefits such as frequent flier points.

Once the insurance is out of the way, you need to deal with medications. Some medications require cooling in transit. Every airline employee will give you a different story; some promise that you can carry it on as hand luggage or store it in the plane's fridge. Forget that, it has never happened to me! Check your luggage and use an icepack for trips where you will arrive at your destination within 6-12 hours; but dry ice works a treat. It does not melt into water (like the icepack) but instead releases an odorless gas. Choose breathable luggage such as soft-sided or canvas, which will allow the gas to escape. Look for dry ice 'bricks' in your Yellow Pages and be surprised how cheap and easy it is. Pick up a one-liter brick on the morning of travel, wrap in a newspaper, put it in with the medicine and voila! At times I was instructed to apply for a dangerous goods permit to carry dry ice in my luggage, but the airline's security was only a phone call away.

[Editor's note: The USA FAA regulations state: Dry ice (carbon dioxide, solid), in quantities not exceeding 2.0 kg (4.4 pounds) per person in carryon baggage or 2.3 kg (5 pounds) per person in checked baggage, when used to refrigerate perishables. The packaging must permit the release of carbon dioxide gas. For checked baggage, the package must be marked "DRY ICE" or "CARBON DIOXIDE, SOLID" and must be marked with the net weight of dry ice or an indication the net weight is 2.3 kg (5 pounds) or less. *Check with the airline you are taking to be sure of what is allowed.]*

Going through customs in foreign countries has never given me a problem. Just be honest, tell them you have medicine (don't refer to it as drugs as that word has bad connotations) and have a letter from your doctor ready in case they ask. Surprisingly, no one has ever asked me for a letter!

Running out of medicine has happened to me frequently; surprisingly it happens despite careful planning. On long backpacking expeditions I had my parents mail me medication, but generally you aim to have enough and

> Make sure your nebulizer will work on different voltages, that your battery charger works *and* that the plug adaptors are suited to your destination.

some to spare. Speak to your doctor to find out if you can do without any for the trip, if there are alternatives, or what to do in case of exacerbations etc. On occasions I have visited foreign pharmacies with my Australian prescriptions and all pharmacists have been very understanding and supplied me with antibiotics and enzymes.

Compared to the cost of USA health care, you will find overseas medical care cheap, albeit lacking in quality. I have visited the odd hospital emergency ward, and in one case was not only treated by a doctor wearing pajamas (Siberia in the 1990s), but also received infrared radiation in my throat which gave me mouth ulcers for two weeks! Avoid hospitals if you can. Local people who cannot understand your problem will offer medication and help. One Hungarian woman insisted on vacuum cupping my back once, and in Holland I get lots of licorice offers.

Make sure your nebulizer will work on different voltages, that your battery charger works *and* that the plug adaptors are suited to your destination. If a nebulizer breaks, you might have to buy one overseas. I have done that a few times and found them to be cheaper there!

Avoid holidays that include inactivity and pollution, but don't waste opportunities that seem impossible at face value, without a little research. For instance, I once took a 10-day cruise that turned out to be very active, and with lots of salty, fresh, sea air, I had no health trouble whatsoever!

Be prepared, let your doctor know you are going, and (tongue in cheek) line up a few friends to help you out when you run into trouble. They will help you when it comes to the crunch! ▲

Walter van Praag is 44 years old and has CF. Currently he is living in Tasmania, Australia. He is better known for his epic book "Coughing the Distance", where he rode 3000 miles across 10 European countries. Check it out at www.amzn.com/0980592011.

In These Trying Times

We know that some people may be going through a hard time with their employment and/or their medical insurance. We are letting you know about a program Genentech is offering called Pulmozyme Access Solutions. Remember, even when times are hard, it's important to keep taking your medication as prescribed by your physician. Focusing on your health is the best way to be there for your family.

Pulmozyme Access Solutions is Genentech's commitment to cystic fibrosis patients. They are here to help find a way for you to get the Pulmozyme your doctor has prescribed.

- **Do you have questions about your insurance coverage for Pulmozyme?** They can help you navigate benefits, coverage or reimbursement issues.
- **Have you recently started Pulmozyme or changed insurance companies?** The StarteRx Kit is a free, 30-day supply of Pulmozyme, nebulizer and educational materials provided to patients initiating therapy while insurance coverage is ascertained.
- **Do you need help with your co-pay for Pulmozyme?** They can refer you to independent, non-profit organizations that provide co-pay assistance and help you with the application process.*
- **Are you uninsured, has your insurance company denied coverage for Pulmozyme or have you met your annual or lifetime insurance cap?** Genetech Access To Care Foundation provides Pulmozyme free of charge for eligible patients without insurance coverage.

If you answered "yes" to any of these questions, Genentech specialists can help you or someone you know. Call **(800) 690-3023** from 6 a.m. to 5 p.m. PT, Monday-Friday, or visit **PulmozymeAccessSolutions.com** anytime. Check them out if you are in need. They are here to help us out.

*Genentech cannot guarantee co-pay assistance once you have been referred by Pulmozyme Access Solutions. The independent, nonprofit organizations to which patients are referred each have their own criteria regarding eligibility, including financial eligibility. Genentech does not influence or control the operations of these independent, nonprofit organizations, but Pulmozyme Access Solutions can help you navigate the process of seeking co-pay assistance by referring you to an appropriate organization and by assisting with the application process.

Fly With Less Stress

By Andrea Eisenman

I don't like to fly. Not because of fear of the plane crashing or terrorism. Although those are real perils, I can handle those mentally. For me, flying is stressful due to the probability of getting a cold or sinus/lung infection due to poor air circulation on the plane. Along with that there is the possibility of sitting for many hours next to a person who is coughing and sneezing.

I had looked into wearing a mask when I had to fly, similar to one that people wear in hospitals. Those are fine, my pulmonologist tells me, if I want people to think I am sick and then they will stay way from *me*. But to really filter any pathogens or bacteria, I needed to look elsewhere. No mask is 100% prophylactic, but some come pretty close. I found a catalogue that has a few different varieties of masks and respirators with varying levels of protection. That catalog is called *National Allergy Relief*. They are also online at www.nationalallergy.com.

I had tried the masks one can obtain in the hospital and felt constricted in my breathing if I wore it for more than two hours. It made my sinuses feel inflamed and congested. So, I bought a Honeycomb Mask from the above catalog. It is very lightweight and comes with filters that can be replaced. The outside mask part can be washed with a mild detergent and used again and again. I found these masks were easy to breathe through while providing a safe protection from pollutants. The catalog states that these masks are good for purifying the air in car or plane travel. I was sure that it was just a sales pitch. But when I fly, even cross-country, and use this mask, it keeps me from getting sick. It is possible that there is a placebo effect; by wearing the mask I feel that I am doing something protective. This "Honeycomb Mask" costs $22.99 and includes one filter. One filter is good for many uses. You can purchase more filters for additional money. This catalog also offers pediatric masks and other masks with varying degrees of filtration.

> "I found these masks were easy to breathe through while providing a safe protection from pollutants."

ANDREA EISENMAN MASKS HER FEAR OF FLYING.

Wearing the mask: I do not put on the mask near the security area, for fear of having a full-body search! I wear it once I am seated on the plane. I will remove it to eat and drink, then quickly pop it back on. I do wear it to walk to the lavatory as well as inside the bathroom. As I walk to the lavatory, I cannot help but notice the faces of my fellow passengers. They seem peeved that I may have some plague. I try not to care. Once I have deplaned, I remove the mask. I usually will wash it before I use it again.

As my ENT once told me, "I prefer that you not fly at all, due to the poor circulation of air on flights, which puts your health in jeopardy." But, there are some places I travel to that would take too long by train or car. So, I fly to save time and hassle. I know that being on a plane for hours comes with a risk of getting sick. Thus, flying with this mask allows me to travel without the stress of what I might catch; I can breathe easier. ▲

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.

CONVERSATION CORNER

Be Careful Before Doing Home Remedies

By Bracha Witonsky

Having CF, diabetes and an iliostomy, I am used to pain in general, but this time my left ear was really bothering me. It felt as if it needed to be popped – as if I was on an airplane. When I mentioned this to my sister-in-law, she told me to try a piece of garlic in the ear; it draws out the fluid. She does this all the time to her kids and it works. Knowing me, I said, "Come on, the garlic will get stuck inside my ear." My sister-in-law laughed out loud and said, "I never heard of that ever happening."

Well, I was desperate, so I bought garlic and sliced it up and used the big middle piece to reassure me that it would not get stuck in my ear. Two hours later, sure enough I stuck my finger in my ear and, SURPRISE, the garlic was not there! Where did it go? Either it got stuck in my ear, which I knew would happen to me or, like on a normal person, the garlic fell out. So I made some calls and everyone seemed to say that it probably fell out. So I went about my day, thinking and hoping that it just fell out.

For weeks my ear was extremely uncomfortable. But remember that, having CF, we tend to deal with tremendous pain before going to the doctor. So for the next few weeks I picked and Q-tipped my ear trying to ease the pain. The horrible feeling did not go away.

At my next CF doctor's appointment, as I was talking to my doctor, he noticed me fiddling with my left ear and asked, "What's wrong with your ear?" I quickly said, "Oh, I have this terrible pain. Maybe you can take a look and see if maybe I have an ear infection?" So Dr. Robert Giusti and a medical student took a look into my ear. They looked and looked and looked and could not believe what they saw. He said, "This is not an ear infection, but you have something in your ear!" I immediately said, "Oh, please take it out." He said, "What is it?" Embarrassed, I said, "A piece of garlic!"

It took a while, with some interesting tools and the expertise of Dr. Giusti, to finally dislodge the big piece of garlic. What a huge relief. As they were about to throw out the garlic I said, "Wait! Don't throw it out." "Why? Do you want to put it back inside your ear?" asked Dr. Giusti. I said, "No. I want to mail it to my sister-in-law!"▲

BRACHA WITONSKY

Bracha is 33 and has CF. She and her husband, Yonason, live with their two healthy children in Brooklyn, NY.

"It took a while, with some interesting tools and the expertise of Dr. Giusti, to finally dislodge the big piece of garlic. What a huge relief."

> "Denial [of Cayston by the FDA] would leave people with CF with no other option but to take off-label drugs that have never been studied and may be potentially dangerous."

hearing. He told me he had spent his career in the HIV/AIDS field. He explained that when he was in his medical residency many years ago in South Africa he had treated children with CF. He had been frustrated by his inability to do more to lessen their suffering due to the lack of drugs available to treat the disease. When he was asked if he would work on the Cayston appeal, he remembered those patients and agreed to help.

Next the FDA presented reasons why the drug should not be approved. None of the reasons had to do with safety concerns or effectiveness of the drug. The CF Foundation then had the opportunity to testify for 15 minutes. Dr. Bruce Marshall, from the CF Foundation and Dr. Patrick Flume, the Director of the Adult CF Center in Charleston, South Carolina, eloquently spoke about the immediate need for a new inhaled antibiotic in the CF community.

After listening to 8 hours of testimony and questioning it was my turn to testify. I wanted the Committee members to understand that the data points on the charts and graphs they had seen represented real people who had families and needed a new drug now to help extend their lives. I explained that I had wanted to fill the room with people who had CF, but due to cross-infection concerns, that was not possible. I told the Committee that I had spoken to 65 people with CF to make sure I was presenting the concerns of the community. I spoke about growing up at a time when there were no treatments to help me in my fight against CF and only having hot tea and honey to try to stop my almost constant cough. I talked about two people with CF who needed a new inhaled antibiotic, now: Grace, a 12-year-old girl who wakes up at 5:30 a.m. to perform all her treatments before heading to school and Ana, a 28-year-old woman who had been hospitalized five times in the past year and whose only choice for treatment at home was use of an off-label inhaled antibiotic. These two brave young women let me tell their stories and show their pictures to a room filled with hundreds of people they did not know. Their stories made an impact on members of the Committee, many of whom did not know much about CF. I told the Committee there were thousands more with CF who could not wait any longer for a new inhaled antibiotic.

I told them it was unacceptable to deny approval for Cayston, which had shown no safety concerns in clinical trials. Denial would leave people with CF with no other option but to take off-label drugs that have never been studied and may be potentially dangerous.

I told the Committee about my health before enrolling in the Cayston research study. My FEV_1 hovered between 50 and 55. I explained how much I love my work in the CF community and started to cry when I said that before starting the research study my doctor had suggested I stop work to focus more time on my declining health. I told them of the dramatic improvement in my health after enrolling in the Cayston research study. My FEV_1 went up to 80 and has stayed between 75 and 80 percent. I gained 15 pounds because with less sputum I had a better appetite and also did not burn so many calories from coughing.

I told the Committee that the FDA was incorrect when they denied the drug on the basis of there being no unmet medical need in the CF community. I explained that there are many adults, like myself, who were resistant to TOBI as well as others who were sick in the month that they were not on TOBI and needed another inhaled antibiotic to use in that off month. I told them the CF community wanted to know why people with CF in 30 other countries had access to Cayston while people in the US did not have access to the drug.

I told them that they had the power to make it easier for people with CF to breathe and asked them to vote to recommend approval of the drug. The hearing was over and I watched as the Committee voted to recommend that the FDA approve the drug.

We should all be forever grateful to those who testified at the hearing, to those at Gilead who pressed forward and put so much time and effort into winning the appeal and to the CF Foundation for making sure the voice of the CF community was heard.

For more information on Cayston you can go to www.cayston.com. Your CF Care Center can tell you if Cayston is an appropriate treatment. Cayston is administered three times-a-day over a 28-day period and is delivered via a new type of nebulizer know as the Altera Nebulizer system. Each treatment takes approximately 3 minutes to deliver. There is co-pay assistance that should result in people with private insurance paying no more than a $25 co-pay for a one month supply of the drug. For more information on co-pay assistance call: 1-877-7CAYSTON (877-722-9786).

Editor's note: Results may vary from patient to patient. It may take more than one cycle to see a difference. ▲

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

Terra Incognita

PHOTO BY STEPHEN BOYER

October 1980, (CF diagnosis)

December 1998, (Double-lung transplant)

November 2006, (Hemorrhagic stroke)

Pushing forward;
No guide to lead the way
Excited, yet Scary
The world is brand new
New sights, new smells, new everything
New medical terms, new medications, new physical limitations
Some former one or two, also
This is Terra Incognita for me, Undiscovered territory.

– Michelle Compton

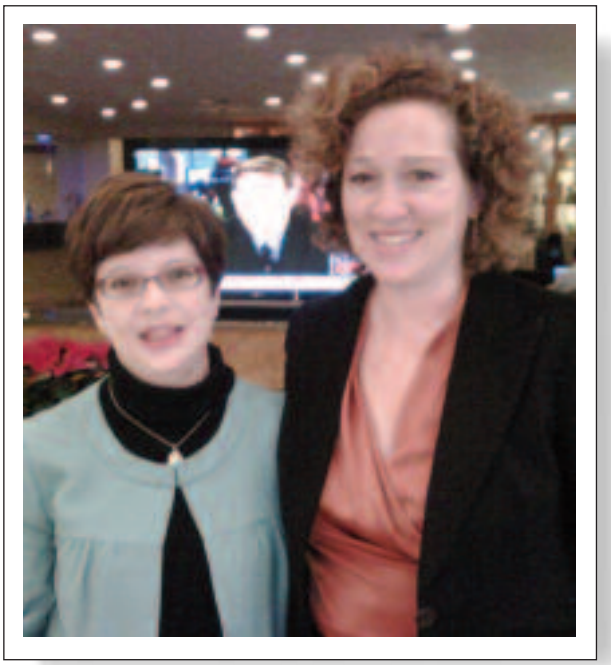
"Through the Looking Glass: Images of Adults with Cystic Fibrosis" and "Caregiver Stories" are projects of Breathing Room, a non-profit organization. Breathing Room hosts these and other projects to facilitate open and candid communication in the CF community, supports the development of a community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

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

FROM OUR FAMILY PHOTO ALBUM...

DARLEEN BOYNTON SHOWS OFF A GIGANTIC SUNFLOWER SHE GREW.

WALTER VAN PRAAG



BETH SUFIAN AND DR. NOREEN HENIG AFTER THE FDA HEARING FOR CAYSTON.

CLOCKWISE FROM LEFT: SHULAMIS ZAHAVA, BRACHA, YONASON AND SHAINA WITONSKY.

Wanted: Stories for the Second Edition of "Taking Flight: Inspirational Stories of Lung Transplantation"

By Joanne Schum

The new year has begun and I am now ready to do the second edition of "Taking Flight". If you or anyone you know – anywhere in the world – with any lung illness is a recipient, caregiver, family member or friend of someone who received a lung, lungs or heart/lung transplant, here is an opportunity to get your story published. I would love updates from those who submitted a story for the first book.

The book will contain stories that the contributors write themselves or, a family member or whomever they would like, may write it. If they are not comfortable with writing their own story, I can do it. That will be accomplished by e-mail or possibly by phone calls.

I will be forwarding information to those who are interested in participating in this project about how to approach story writing. I will offer ideas and hints on what you might want to talk about, as well as information on what copyright is and what the laws are.

Selection of the cover design will be similar to what was done with the first edition. I will ask the contributors of stories to send in their pictures, drawings, photos, or cover design ideas for a great new book cover. The name of the book will remain the same, with the addition of "Second Edition". Again, I will accept designs only from contributors. Also, it will be up to me to choose which design will be used.

Once I recoup the expenses of publication, the profits will be given to organizations, mainly in the lung or donor area. The contributors are the only ones who can make suggestions and I will research the organizations before the profits will be given out to them.

There are so many steps in this process, and I am so excited about being able to do this again. I also have a new Facebook Site. Check it out and join at Lung Transplantation: Taking Flight with New Life http://www.facebook.com/?ref=home#/group.php?gid=245756329913.

Joanne is 46 and has CF. She lives in Webster, New York. You may contact her at: luckylungsforjo@aol.com.

Information from the Internet...

Compiled By Laura Tillman

This issue brings a potpourri of articles from the Internet

NEWS RELEASES

FDA Approves Cayston ® (Aztreonam for inhalation solution) for the Improvement of Respiratory Symptoms in Cystic Fibrosis Patients with Pseudomonas Aeruginosa First New Inhaled Anti-Pseudomonal Therapy Approved for Cystic Fibrosis Patients in More Than 10 Years

Gilead Sciences, Inc. announced that the U.S. Food and Drug Administration (FDA) has granted marketing approval for Cayston(R) (aztreonam for inhalation solution) as a treatment to improve respiratory symptoms in cystic fibrosis (CF) patients with Pseudomonas aeruginosa (P. aeruginosa). Cayston's safety and efficacy have not been established in pediatric patients below the age of 7, patients with forced expiratory volume in one second (FEV_1) of less than 25 percent or greater than 75 percent predicted, or patients colonized with Burkholderia cepacia.

Cayston is administered at a dose of 75 mg three times daily over a 28-day period and is delivered via the Altera(R) Nebulizer System, a portable, drug-specific delivery device using the eFlow(R) Technology Platform, developed by PARI Pharma GmbH. Gilead also announced today the establishment of a program designed to minimize barriers to access for Cayston for uninsured, privately

Continued on page 25

Voices from the Roundtable

Young Adult CF Anxiety

By Darleen Boynton

Recently, on a CF support group Web-site, there were questions about post-traumatic stress disorder due to living with the diagnosis of CF.

I can relate to this issue. I am 44 years old and was diagnosed with CF the summer after 8th grade. We lived in a small town and word spread to everyone pretty fast. It was not very fun getting "special" handling for a problem that had not existed before, as far as I was concerned.

When I was in high school, the CF clinic psychologist was always asking stupid questions about how I felt about the fact that I would die before I graduated from high school. I told him he was an ass. Then he wrote I was in denial. When it was pretty clear that I was likely to live long enough to graduate from high school, he started bugging me about how I felt about the fact that I would not live long enough to graduate from college. He even questioned if I was well enough to go to college.

I was really upset in French class one day, when the class was talking about what the world would be like in the year 2000. I could not imagine that I was going to see that day, since I would be 30 years old. At the time the oldest person I had ever heard of with CF was 24 and she was not really doing very well. All the "old" people with CF were in their early 20s. None of them made it to age 25. At 18, I was leading a pack on the pediatric floor of St. Frances hospital as "the big kid".

Right after I graduated from high school things were kind of at loose ends for me. All the negative death talk, my parents' divorced status, my father's remarriage and other struggles all kind of held me back. My boyfriend was a huge encouragement, though! He told me that I would love going to college and went to a community college where he picked up a course catalog and an application for me. His encouragement really changed my life. He did not care about CF, my parents or all the other negatives. He just saw me as a beautiful soul that complimented his own talents.

I did graduate from college! I did get good grades! I did have a job in my chosen field of geography waiting when I graduated! Hurray!

That CF anxiety was always on my mind though. It was tough working as a geographer. I had very little time off, it was high stress and I had poor health insurance. None of that was a very good combo. Soon I changed fields and started working at a lower paying job that had great benefits and great time off. It really hurt my ego to drop being a geographer, but in the long run it has proven to be a good idea.

When I hit 30 and had been missing out on things, I gave up waiting for bad things to happen and started to really live with confidence. I bought a condo, had my occupation lined up, had settled into living in my transplanted state of Michigan, had adult friends, etc. I was living about as well as anybody else.

Until I hit 40, though, I still was looking over my shoulder as far as relationships go. It was the newsletter, *CF Roundtable,* that got me thinking again about a relationship that could lead to marriage. For the first time I was seeing other people with CF living as adults. It was

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.**

really very freeing. My thing about relationships was not only about CF. It also had to do with my parents' model - not very happy.

I also found a conference call chat group in New York made up of a lot of married people who had CF. I loved hearing about married people and thought – well, maybe I could look into this. I would like to have a life partner, too.

> "To young adults with CF who are questioning their future and kind of putting things on hold, I would encourage you to put your mind on "activate". "

There are plenty of people who do not have CF who do not do well in relationships, but look at all these CF people who are married - they even had kids. I never had known before that it was sort of safe for a CF woman to have children. I also started noticing that I knew a lot of people who were maintaining successful relationships. Hmmm...long term relationships can be satisfying, not terrifying.

Three years ago I fooled around with an on-line dating service. I met a special man this way. We have been together for 2 1/2 years. I told him about CF before we met. It has never been an issue for him. My health never is smooth for very long, so he has seen me go through a lot of things and taken it all in stride. It makes me who I am.

In addition to the problems I carry around with CF, I also have CF-related diabetes (CFRD), Sweet's syndrome, superior vena cava syndrome and kidney stone issues - so I am not just blowing smoke. I *know* CF is a pain. Again, though, it makes me who I am. I would be the first to say that I am not my body, but certainly my body does get a vote on what is going on.

When I do IVs and get that two or three days of exceptional breathing and all the energy those good breaths bring, I always wonder why everybody else is always so tired. What could I be doing, if I did not have these burdens? I probably would implode from doing too much. Carrying around fear does not help. I used to have tons of fears. I finally understood I cannot control all the outcomes. So, I might as well find something to enjoy and be grateful for every day. I might as well think about the birds, notice the moon. I might as well help my neighbor. Worry never helps anybody or anything.

To young adults with CF who are questioning their future and kind of putting things on hold, I would encourage you to put your mind on "activate". Check out the Web and see all the kinds of things people with CF are doing. Look for role models of living with or without CF. Learn how to examine your own thoughts and learn how to keep negative thinking under control. Learn overall healthy life skills. This newsletter is full of good tips every issue! Nobody can predict the future. Don't rob yourself of living today! Enjoy yourself today! I wish you well! ▲

Darleen is 44 and has CF. She lives in Ann Arbor, MI. Her latest accomplishment has been to learn how to ride a high wheel bicycle.

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 USA.

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 subcommittee (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.

Financial Decisions Facing Adults with CF

By Marcus Harris

In 1981 I was diagnosed with cystic fibrosis (CF), at the youthful age of eight. By the time I was nine, I had been made aware of my very short life expectancy by my peers at school, whose parents had told them about CF. Then when I used to go door to door trying to raise money for the CF Walk Relay, I remember the neighbors saying, "Oh you're the boy with CF. I had a cousin who died of CF when he was about your age." Those words did not fall lightly upon a youngster who just wanted to be like the other kids who were more concerned with Atari Games than mortality.

From my early life experiences, I went into CF-hiding and kept my health a closely guarded secret. I did not share with my best friends, or cousins, or family members. CF also greatly impacted the way in which I lived my life. I knew there would be no ramifications for lack of participation in school and I could spend the majority of my time enjoying myself in lieu of doing homework. By the time I entered high school, the average life expectancy for a CF patient was around 18-20, still just a few years ahead of my age at the time. I did not bother preparing for college, getting ready for SATs, obsessing about what my major would be in college and what I might like to do for a living afterwards.

I graduated high school and was still in good health - for a CF patient. I had some quick decisions to make and opted to attend the local Community College. I earned a 4.0 GPA my first semester, retained a high GPA and transferred to Towson University in Maryland. I graduated with a high GPA and a dual major in Business Management and Marketing. I was a professional tutor to struggling students. I started my own boat detailing business during college. I was in the mountain biking and snow skiing clubs, and lived a pretty normal college life going to parties and dating. I was alive and still feeling well.

MARCUS HARRIS

Upon graduation I took a job selling software to schools. I was making good money but not saving a thing. I could not break away from the "live for today" mentality that had driven much of my thinking throughout the course of my life. The turning point in my financial life stemmed from my desire to experience life to its fullest and to travel, drive a Porsche, dine at nice restaurants, try scuba diving and to ski in Aspen. All the things on my "bucket list" cost money and some of them would cost a lot of money. In order for me to attain the experiences that I desired, I would have to save money, make it grow, and apply patience – all of which I had never done. Once I arrived at these conclusions, I delved right into learning about money, investing, stocks, bonds, real estate and careers that paid higher wages.

I really started investing by 1998. I was building a little nest egg and the markets were working for me. I took a job in the "dot.com" industry in 2000, and was granted stock options from my company. I was making a good living and living a frugal existence. The more I could earn, the more I could save, and the less I could spend would net my goals sooner rather than later. In 2001 the stock market crashed and I lost over 50% of my personal investments, my company stock went from $186 per share to $6 and my options were worthless; then I lost my job and handsome income. I took my measly severance and the investment money I had remaining, and drove across the country with a friend for about a month.

Upon my return I took a job selling printers and copiers, thinking it would be far more stable and that every business would always need that equipment. From that day, I started over. I lived frugally; I saved a portion of each paycheck and participated in the company 401K plan. I ate peanut butter and jelly for lunch and pretzels with cheese for dinner for months in order to get ahead again. Now I was twenty-seven years old and still doing well with my CF and CF-related diabetes (CFRD).

I had been renting a portion of a small apartment building with a friend

> "I think we all need to consider buying a house, getting married, saving for retirement and budgeting for a life that may be far longer than we had ever imagined."

from college in a borough of Baltimore City. My landlord told me he would be selling the house and moving to Florida. I had been renting from him for five years and was not ready to move. I got approved for a mortgage and a few months later bought the building from him. I continued to live in the apartment with my friend and had two other apartments now under my management. My roommate and the other tenants were covering the entire mortgage and paying down the principal by over $500 per month. I saved all the monies I had previously been using for rent and invested the money in stocks and mutual funds. I was continuously researching how to get a better return on my money and how to become a better investor. The property continued to appreciate over the next several years and rents in the area increased handsomely.

In 2002 I met a lovely woman, Lori, and we became engaged seven months later. We lived in the city together for a short period, then bought a house in the "burbs" after getting married. The rent we were receiving from all three units of the rental property covered the note on the rental property and the mortgage on our new house. When Lori and I married, I arranged our finances so that we lived off my income and saved nearly 100% of hers. The key was not to increase our lifestyle proportionately with the change in our incomes.

I changed jobs to become a financial planner and earned the CERTIFIED FINANCIAL PLANNER designation after the required three years of experience. We opted to have children and were blessed with twins after a complex in-vitro process. Today I am 35 years old and still in good health. I am faced with not qualifying for a life insurance policy, trying to save for college, saving for retirement, having an emergency fund for health issues, trying to get ahead financially for my wife and children, paying high medical costs and insurance deductibles, and many of the things that all CF adults are now facing.

Because I took an early interest in my own financial situation, I am better off today. I think we all need to consider buying a house, getting married, saving for retirement and budgeting for a life that may be far longer than we had ever imagined.

My dream today is to educate people about getting financially savvy early in life, and to help other CF patients plan for a longer financial life. I have set up a Skype account to conduct meetings remotely and to avoid close contact with other CF patients. I hope others can benefit from my experiences, financial considerations and achievements. ▲

Marcus, Lori and their twins, Hannah and Hamilton, live in Sparks, Maryland. You may contact Marcus at: Mharris@financialconsulate.com or by phone at: 410-773-9395.

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.

WELLNESS

Wherever You Go, There You Are (stolen from Jon Kabat-Zinn)

By Julie Desch, MD

I had to laugh when I saw the focus topic for this issue, "Traveling For Work or Pleasure With CF". I was traveling at the time, but it wasn't really for work or pleasure. I started to think of several different topic ideas regarding the intersection of travel and wellness: eating well on the road, figuring out ways to exercise on the road, motivational strategies to do treatments while on the road. All are definitely good ideas and maybe future topics for this column.

However, this trip was somewhat of an emotional challenge for me. I was trying to be helpful to my aging parents as they (and we, their children) learn to live with their increasing needs. While I did manage to exercise, and do treatments, and eat well during this week away from home, by far the most helpful thing I did for myself was to maintain my mindfulness practice. So, this is what I have chosen to write about.

"Wherever You Go, There You Are" is the title of a great book by Jon Kabat-Zinn, who is the founding director of the Stress Reduction Clinic and the Center for Mindfulness in Medicine, Health Care, and Society at the University of Massachusetts Medical School. In 1979, he developed a technique called Mindfulness Based Stress Reduction (MBSR), to which I was introduced 13 years ago. MBSR has been demonstrated to be very effective in the treatment of a wide range of conditions related to illness, chronic pain, and stress-related disorders. It is now taught at over 250 medical centers in the US and across the world. Perhaps you have heard of it?

Back to my own introduction to MBSR: Let's set the scene. I was a practicing Pathologist in my mid-thirties, and was experiencing, for the first time in my life, significant health problems related to my CF. In addition, I was about to become a mother. I was seriously considering giving up my career to devote my time to my health and my forthcoming child, and my stress level was hitting the roof.

Fortunately, the medical center where I worked was one of the many that offered the 8-week MBSR program, and I signed up. Now, I'm not going to say that it cured my stress and I have been in a constant state of bliss ever since. However, what did happen was that I established a meditation practice that I continue to this day. This practice has become so significant to me that I just completed a teacher training practicum in MBSR, and I am about to start co-teaching a class this month.

There is no question in this day and age that there is a significant connection between the mind and the body. There is now even a field of "mind-body medicine". The unconscious and the conscious goings-on in the brain definitely have ramifications felt in the body. If these brain "events" are stressful to the body in an ongoing way (i.e. a chronic health challenge), there is an elevated level of several stress hormones. One of them, cortisol, can lead to significant (negative) changes is how we feel, think, and in how our immune systems function. So learning to handle stress skillfully is of great importance to not just how we feel, but to the health of our bodies. For this, a mindfulness practice can be quite helpful. With a regular mindfulness meditation practice it is possible to observe conditioned dysfunctional patterns of thinking. As this capacity develops over time it becomes possible to develop new ways to respond to, rather than react to, stress. The end result is an elevated "threshold" for what is perceived as stressful.

As I wrote in the last *CF Roundtable* edition, mindfulness is deceptively simple. *It is simply paying*

> *"Learning to handle stress skillfully is of great importance to not just how we feel, but to the health of our bodies."*

JULIE DESCH, MD

attention on purpose to whatever is happening in the moment, without the filters or lenses of judgment. Through mindfulness we cultivate awareness of the mind (thoughts and emotions) and sensations in the body, and learn to be with whatever is present.

Last time, I discussed mindfulness with regard to the act of eating. This is a great, very hands-on introduction to the practice. It becomes even more interesting when we turn mindfulness to our thoughts and emotions, and to how we sense into and move our bodies. The eight-week MBSR class is a proven systematic method for teaching this.

When it comes to living with CF, I have taken a "throw down the gauntlet" approach. This means that I (try to) do whatever is in my power to both live well with the disease, and to learn whatever it is that CF is teaching me in the moment.

There is a growing body of evidence that meditation (and other spiritual practices) improve the immune system. So for me, that means that meditation automatically goes on my list of daily activities (along with exercise, treatments, a constant quest to gain weight, frequent naps, etc).

But the more important reason that I meditate is that it is providing a catalyst for learning the lessons of living with illness. There is a certain perspective that can be found in a meditative state that allows me to be more at peace as I grapple with the impermanence of my state of health, my parents' increasing troubles, and pretty much whatever happens in this life.

If you are interested in learning more, google MBSR in your area or go to the Center for Mindfulness website (http://www.umassmed.edu/Content.aspx?id=41252). Or, if you are interested in being in a group with other people with CF (and have a computer), I will be starting a "virtual" MBSR class this summer for people with CF. We will be using a web-based platform where virtual mindfulness classes are taught at a very reasonable cost. Multi-resistant bugs be damned!

When it is all set up, I will announce it on my blog at www.sickandhappy.com. Hope to see you there! ▲

Julie is 49 and is a physician who has CF. She is a Director of USACFA. You may direct your questions regarding CF-related health issues to her at: jdesch@usacfa.org.

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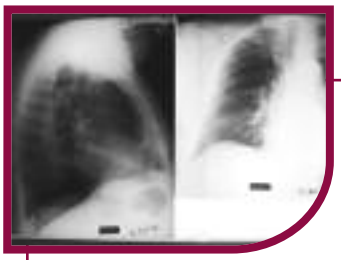

A DEEP BREATH IN
What Defines a Vacation?

By Debbie Ajini

Previously, I have written three columns on traveling. The first two covered traveling with oxygen and the third on deciding just how far to go away from home. So I obviously have a lot to say on the subject! I have to admit, as I got ready to write this column, and in my first few drafts, it was getting to be kind of a downer. In the past I talked about how much my husband and I loved to travel. I talked about how we went to California, Las Vegas, and on a cruise. I had adapted to my limitations and figured out how to travel with oxygen. I had found places to go in the states that allowed us the comfort of being close to a CF doctor.

When I find myself thinking of taking those vacations now, it seems more daunting both physically and financially (darn economy). It is interesting because my health has not changed that much since those trips. But the idea of traveling anywhere that requires flying takes me farther out of my comfort zone than it used to. While two years ago, traveling with oxygen seemed easy, now it is a bit more intimidating. I am more afraid to be far from a CF care center and would prefer to stay by my CF care center.

Usually people travel to get away from it all. To not have things to worry about. This is much harder to do with CF. We usually can't leave CF behind like a spouse can leave work behind. I would love to get away just to the next town if it meant I could leave the meds, the O2 and the lack of energy behind. But, alas, that is not my story right now; we are just talking same stuff, different scenery. So how to reconcile the traditional definition of a vacation with my reality today? I go between "Pity Party" and "This is Something I Won't Let CF Have Total Control Over".

So, as I started this column I was getting more and more down about what I could not do or was not comfortable doing. Traveling with all the various equipment for CF gets annoying. I think that overnight trips tend to be more work than they are worth. Packing and schlepping all my stuff plus getting off my schedule makes it so that I need two days at home to recover when we get back. I have figured out how to travel with oxygen. I know it can be done. My husband has mastered the packing of the car to fit all my stuff. I know the things to take with me to make it easy to keep up my routine. So it seems the only thing that is changing is the destination. Not so much the journey to it and certainly not whether or not I have fun once I get there.

> *"Packing and schlepping all my stuff plus getting off my schedule makes it so that I need two days at home to recover when we get back."*

The challenge is to not want something I simply can't have right now. I know it all will be worth it someday and I know I have been very fortunate in the travel I have done over the years. Can that really replace the experience of traveling to a tropical island? I am determined to find a way. To find a balance.

At this point I paused and asked myself three questions: Why do I like to travel? What do I enjoy about it? Is it possible to create a new version of what that looks like while meeting my health needs?

Let's start with the first two questions.

Here is what I like/enjoy about traveling:

1. Relaxing with my husband
2. Change of scenery and weather, sunshine being the best choice (Sometimes just new scenery is enough!)
3. Chance to eat good food, try new food
4. Taking photos

DEBBIE AJINI

TILLMAN *continued from page 17*

5. Visit a tourist attraction
6. Shop for souvenirs
7. Meet other people doing the same thing, laugh with them – often

Once I broke it down that way I realized it was much more realistic to take a "vacation" than I may have thought. I decided I just need to be more creative in my approach.

As for the third question, I had already answered it. We took a trip to Niagara Falls in September. In planning the trip, I went through all the thoughts I mentioned earlier. I had the pity party. I was frustrated. But I wanted to go on vacation more than all that, so we made a plan that worked for us. It was a nice trip, not too far from home. There was more time spent outside and in the sun. Just being in a new place was nice, trying new food. This trip was different because we chose it to be somewhere we could drive to. That helped us feel more comfortable. Yet it was a beautiful change of scenery and we had a full day of wonderful sun. Naturally, we saw quite a few tourist attractions and I have the photos (and souvenirs) to prove it. The days were dictated by my treatments, the plans dictated by walking distance. I usually needed a nap. So did hubby. But we made the most of it. So I know it can be done. Not the dream way. But a way.

So, for now, I will travel in smaller circles. I will enjoy the local culture. I will accept that doing treatments and taking naps are just a part of it all. I will enjoy the destination. I will put a picture of Fiji (our Dream vacation post-transplant) where I can see it just so I am reminded of what possibilities lie ahead. That it is worth it to do this now, so later, when my travel circle bursts wide open, I will be ready. And I promise to send a postcard when I get there! ▲

Debbie is 39 and has CF. She is a Director of USACFA and is the Secretary. Her contact information is on page 2.

insured and government-insured people with cystic fibrosis.

Additionally, Gilead is launching the Cayston(R) Access Program, a call center developed with the Cystic Fibrosis Foundation Pharmacy. The program will assist people with cystic fibrosis and members of their care team with insurance verification, referral to participating specialty pharmacies, claims support and co-pay assistance. For information about the Cayston Access Program, call 1-877-7CAYSTON (877-722-9786) or visit www.cayston.com.

FDA Advisory Committee Supports Use of Aztreonam for Inhalation Solution for Patients with Cystic Fibrosis

Gilead Sciences, Inc. announced that the Anti-Infective Drugs Advisory Committee of the U.S. Food and Drug Administration (FDA) has recommended that aztreonam for inhalation solution be approved for the treatment of infections due to Pseudomonas aeruginosa (P. aeruginosa) in patients with cystic fibrosis (CF). The committee voted 15 to 2 that Gilead has provided sufficient evidence of the safety and efficacy of aztreonam for inhalation solution. The panel also voted 17 to 0 that aztreonam for inhalation solution 75 mg three times daily is a correct dose and regimen. The recommendations of the Advisory Committee are not binding but will be considered by the FDA as the agency completes its review of Gilead's application. The FDA has established a target review date, under the Prescription Drug User Fee Act (PDUFA), of February 13, 2010. In the interim, Gilead will continue to make the product available through its Expanded Access Program in the United States.

http://www.gilead.com/pr_1364662

PARI Pharma's Altera Delivers Gilead's Cayston, Approved By The U.S. FDA For The Improvement Of Respiratory Symptoms In Cystic Fibrosis Patients

Cayston is only approved for use with the Altera Nebulizer System, which has been optimized specifically for Cayston. Altera Nebulizer Systems are consistent with the specifications of the customized nebulizer systems based on eFlow Technology that were used exclusively in all Cayston clinical trials. The Altera Nebulizer System uses eFlow Technology to enable highly efficient aerosolization of medication via a vibrating, perforated membrane that includes thousands of small holes producing the aerosol mist. Compared to other nebulization technologies, eFlow Technology produces aerosols with a very high density of active drug, a precisely defined droplet size, and a high proportion of respirable droplets delivered in the shortest possible period of time. The Altera Nebulizer System and eFlow Technology are proprietary to PARI Pharma.

http://www.medicalnewstoday.com/articles/180169.php

FDA Grants Orphan Drug Status to Ciprofloxacin Dry Powder Inhaler for the Treatment of Cystic Fibrosis

Bayer Schering Pharma AG, Germany, announced that an orphan drug designation has been granted by the U.S. Food and Drug Administration (FDA) for the ciprofloxacin dry powder inhaler (DPI) for the management of chronic pulmonary infections due to *Pseudomonas aeruginosa* in cystic fibrosis (CF) patients. Ciprofloxacin DPI is an innovative drug-device combination. It combines ciprofloxacin dry powder that is formulated using Novartis'

Continued on page 27

The Medicare Part D Maze

By Sue Connors

This article is about Medicare Part D drug plans, the coverage gap and co-pays. It is based on talking to staff at Medicare, talking to staff at the Part D Drug Plans and from the personal experiences of people who are trying to navigate thru this Medicare Part D Drug Plan maze. The Medicare Part D drug plans were signed into law in 2006. They are beneficial but still need some major changes. Most people on Medicare feel that the coverage gap should be eliminated from these plans. Very few people that reach the yearly coverage gap move out of it. All states offer two or more drug plans to choose from. All of the Part D drug plans are administered by insurance companies such as Aetna, United Health Care, Humana, Community Rx, etc. Medicare does try to resolve issues that occur with the Part D plans.

How to Find a Part D Plan

I would suggest going to <Medicare.gov> and clicking on the Prescription Drug Plan Finder. Enter your zip code and all the medications you take, along with the dosages. A listing of the Part D plans in your area that will cover your medications should come up. Each listing should have the name of the Part D drug plan, their phone number, monthly premium, your annual cost for the premium, the cost of your medications, the plan's customer service rating (1 thru 5 stars), and whether they offer coverage during the gap. Usually the plans that offer coverage during the gap will have a higher monthly premium. The monthly premiums for these plans could be approximately $78 to $100 per month. Most of them will cover only generics during the gap.

The Coverage Gap

All Medicare Part D plans have a coverage gap and, hopefully, this will be eliminated by some type of healthcare reform bill. For 2010 you will have to pay a $310 out of pocket deductible for your Part D plan. Once you have paid the $310 deductible, you should have relatively low co-pays until your prescription drug costs reach a total of $2,830. When you and your Part D plan have paid $2,830 you will be in the "coverage gap". Once you have reached the coverage gap you will have to pay $4,550 out-of-pocket for your prescriptions. Once you have spent $4,550 for your prescriptions you reach the "catastrophic" phase of coverage.

Financial Help with Drug Plan Costs

There is a Low Income Subsidy program through Medicare. If you qualify for the Low Income Subsidy then you will have lower monthly premiums, lower drug co-pays and, probably, won't have a coverage gap. I would recommend going to <Medicare.gov> for more information regarding the Low Income Subsidy.

Formulary and Appeals

All of the Part D plans have a formulary of medications that they will cover. They are required to have two medications in each therapeutic class. If you are on a medication that is not in their formulary they will ask you to try the ones in their formulary. If you have tried the medications in their formulary and they don't work out for you, then you will need to submit an appeal to get the medication you need covered. You or your doctor can submit an appeal to get the medication covered. If your doctor submits the appeal, the Part D plan is supposed to process it quicker. The appeals process is supposed to be short but, often, it is long and tricky. My doctor and I were recently working on an appeal to get Creon® covered. The appeals department lost the paperwork three times, then they sent back a response stating I was not covered (I was). I finally filed a complaint against them with Medicare. I am still waiting to hear back about the Creon and it's been six weeks since the appeal started. I would suggest having your doctor give you a copy of the appeals that are faxed to the insurance company. Then you can call the insurance company every three days to check on the status of the appeal. This should help speed things up a little and it lets them know you are serious about this and that you want an answer.

Ways to Save Money and Stay Out of the Gap Longer

Here are a few tips for staying out of the coverage gap longer. Generic medications are much less expensive than brand names, in most cases. My current plan will cover generics during the coverage gap. I need to stay out of the coverage gap for as long as possible so my Part D plan will cover name brand medications for me, such as antibiotics when I need them. One thing you can do is ask your doctor to write you prescriptions for generic medications whenever possible. Then call around to your local pharmacies and check the prices for each

TILLMAN *continued from page 25*

of your generic medications. Ask them what the cost is for a 90-day supply because this can save you money, too. I would also ask them if they have a prescription savings club. I know that Walgreen's has one and joining it can save you money on prescriptions. I have also found generic Zantac® and generic Prevacid® at Sam's Club for a great price.

Organizations that Help with Co-pays

The following organizations will help with co-pays for prescriptions and/or insurance premiums. Please contact the ones you are interested in and ask what services they offer.

1. Patient Services Incorporated 1-800-366-7741, helps with insurance premiums.

2. Patient Advocacy Foundation 1-800-532-5274, helps with prescription co-pays.

3. Patient Access Network 1-866-316-7263, helps with prescription co-pays.

4. Needy Meds 1-978-865-4115, helps with co-pays for insurance and prescriptions.

5. National Organization of Rare Disorders 1-203-744-0100,helps with insurance and prescription co-pays.

6. Caring Voice Coalition 1-888-267-1440, helps with prescription co-pays for people on Medicare.

There are several other organizations that will help with co-pays for insurance and prescriptions. You can find them by doing an internet search. ▲

Sue has CF. She lives in Reynoldsburg, Ohio, with her husband, and is a part-time freelance medical writer.

Proprietary PulmoSphere® technology with an innovative easy-to-use delivery inhaler. Ciprofloxacin DPI is in Phase II development and is being studied for its safety and potential to improve lung function, as measured by the forced expiratory volume in 1 second (FEV_1), in patients with CF. In Phase I studies with ciprofloxacin DPI in pediatric and adult CF patients, ciprofloxacin has been shown to reach high concentrations in the lung with very low systemic exposure following single and multiple dose administration. Initial Phase I study results showed that ciprofloxacin DPI was well tolerated in CF patients without clinically relevant drug treatment related adverse effects. A multinational Phase II study in CF patients is ongoing with the primary end point of improvement in lung function, measured by FEV_1.
http://tinyurl.com/y9cdb5x

Defunct CF drug reborn

A cystic fibrosis drug that seemed destined for death when its company faced financial troubles is being revived by another company. A new company launched by a veteran of the defunct company (Altus Pharmaceuticals) plans to submit the drug, a pancreatic enzyme replacement therapy, to the US Food and Drug Administration for approval. Liprotamase, Altus's drug, was based on microbial enzymes rather than those extracted from pig pancreas, and could be taken in a single pill, rather than the five or so patients generally take with each meal. Phase 2 results for the drug in 2006 were promising. But Phase 3 results two years later were not quite optimal; although the trial met its statistical endpoint — a significant improvement in fat absorption (a measure of CF patients' often-compromised ability to take in nutrients) — the average improvement of 15 percent was less than the 20-30 percent the FDA had requested. Altus gave rights to the drug to the Cystic Fibrosis Foundation in January 2009, but just a few months later, CFF licensed the drug to Alnara Pharmaceuticals. Last October, about a month after Altus said it would end operations, Alnara announced the trial's completion with positive results. Alnara plans to submit the paperwork for FDA approval this month.
http://www.the-scientist.com/blog/display/57209/

CF Investigational Drug VX-809 Shows Encouraging Results in Phase 2a Trial

Vertex Pharmaceuticals Incorporated announced today results from a Phase 2a trial of VX-809, an oral investigational drug that aims to correct the basic defect in cystic fibrosis. VX-809 was found to be well-tolerated and to reduce sweat chloride levels — a key indicator of CF.

The 28-day, Phase 2a trial of VX-809 examined the drug in cystic fibrosis patients who have the Delta F508 gene mutation, the most common mutation in CF. The study focused primarily on the safety and tolerability of the drug and changes in sweat chloride. A reduction in sweat chloride levels in the Phase 2a data suggests that VX-809 may improve the function of CFTR, the faulty protein in CF.

The VX-809 data further supports our hypothesis that small molecules can be used to treat the underlying genetic cause of cystic fibrosis."

The data from this trial pave the way for future studies of VX-809, including testing the therapy in com-

Continued on page 28

bination with VX-770. Also developed by Vertex, VX-770 is an oral investigational drug that showed encouraging Phase 2 results in restoring the function of CFTR in patients with the G551D mutation of CF.

Research in the laboratory suggests that using two therapies in combination may increase CFTR function in cells with the Delta F508 mutation when compared to using a single therapy alone.

The first trial examining VX-809 and VX-770 in combination in cystic fibrosis patients is currently in the planning phases, and is expected to begin in the United States in the second half of 2010.

In addition, Vertex is further reviewing the Phase 2a data and may explore the option of studying VX-809 as a single drug in higher doses in a separate clinical trial.

http://tinyurl.com/yf5nn8e

Researchers restore some function to cells from cystic fibrosis patients

In an encouraging new development, a team led by Scripps Research Institute scientists has restored partial function to lung cells collected from patients with cystic fibrosis. While there is still much work to be done before the therapy can be tested in humans, the discovery opens the door to a new class of therapies for this and a host of other chronic diseases. The new study, performed in collaboration with a large number of cystic fibrosis investigators across the United States and Canada, showed that a compound called suberoylanilide hydroxamic acid (SAHA), which is already approved by the U.S. Food and Drug Administration as a treatment for lymphoma, can restore about 28 percent of normal function to lung surface cells with the most common, yet severe, cystic fibrosis mutation that results in complete loss-of-function in homozygous patients (those receiving a copy of the mutated gene from both parents).

http://www.physorg.com/print179328978.html

Researchers identify new method to tackle bacterial infections

Researchers from the University of Groningen have clarified the structure of an enzyme that disturbs the communication processes between bacteria. By doing so they have laid the foundations for a new method of tackling bacterial infections such as those found in cystic fibrosis. Although bacteria are simple single-celled organisms, they are capable of communicating with each other. Bacteria talk to each other by exchanging tiny hormone-like signal molecules. By means of this process of 'quorum sensing', the activities of a large group of bacteria are synchronized. Thus bacteria can adapt quickly to changes in their environment such as the running out of nutrients or the arrival of rival microorganisms. The production of factors that determine the virulence of a bacterium is also controlled by these signal molecules. This enables bacteria to remain invisible to the immune system in the early stages of infection. As soon as the group of informed bacteria - the quorum - is sufficiently large, the attack on the infected host is initiated by starting up the production of toxins and other virulence factors. The quorum-quenching acylase of which the Groningen research team has determined the structure is capable of cutting off these signal molecules. As a result, the communication processes between pathogenic bacteria are disturbed. The enzyme turns out to suppress the virulence of the lung bacteria *Pseudomonas aeruginosa*, the most important pathogen for cystic fibrosis.

http://tinyurl.com/ybcmj54

Researchers Discover New Ways to Treat Chronic Infections

Researchers at Binghamton University, State University of New York, have identified three key regulators required for the formation and development of biofilms. The discovery could lead to new ways of treating chronic infections. Biofilms — communities of bacteria in self-produced slime — may be found almost anywhere that solids and liquids meet. Biofilms are implicated in more than 80 percent of chronic inflammatory and infectious diseases caused by bacteria, including pulmonary infections in cystic fibrosis patients. Biofilms are difficult to eradicate with conventional antimicrobial treatments since they can be nearly 1,500-fold more resistant to antibiotics than planktonic, free-floating cells. Researchers documented a previously unknown genetic program composed of several regulators by looking for changes in phosphorylation patterns in *Pseudomonas aeruginosa*. These regulators cannot only be used to stop the development of biofilms at various stages in their growth but also to revert established biofilms to an earlier developmental stage. In addition to regulators required for biofilm formation, the researchers recently identified a regulator that is only expressed in biofilms and which seems to be responsible for regulating antibiotic resistance. The resistance of biofilms can be modulated by overexpressing or inactivating this particular regulator.

http://tinyurl.com/yeujyfq

Defective Signaling Pathway Sheds Light on Cystic Fibrosis

In a study that could lead to new therapeutic targets for patients with cystic fibrosis, a research team from the University of California, San Diego School of Medicine has identified a defective signaling pathway that contributes to disease severity. In the study, published in the journal *Nature Medicine*, the researchers report that defective signaling for a protein called

the peroxisome proliferator-activated receptor- (PPAR-γ), as a result of reduced levels of prostaglandins that activate the receptor, accounts for a portion of disease symptoms in cystic fibrosis, and that correction of the defective pathway reduces symptoms of the disease in mice. When the researchers treated mice with cystic fibrosis with the drug rosiglitazone, a thiazolidinedione drug that binds and activates PPAR-γ, gene expression was largely normalized and survival improved. The drugs also corrected part of the inflammatory process in the tissue. Deleting the PPAR- protein in the intestine of mice worsened the disease, leading to mucus accumulation in the intestine. Additionally, the researchers found that activating PPAR-γ could increase bicarbonate production in the intestinal tissue by increasing the activity of bicarbonate-producing enzymes called carbonic anhydrases.

http://www.newswise.com/articles/view/561339/?sc=mwhn

http://www.healthfinder.gov/news/newsstory.aspx?docID=636080

TREATMENTS

Aminoglycoside antibiotics restore CFTR function by overcoming premature stop mutations. Marybeth Howard, Raymond A. Frizzell & David M. Bedwell. *Nature Medicine* 2, 467 - 469 (1996)

Cystic fibrosis (CF) is caused by mutations in the gene encoding the CF transmembrane conductance regulator (CFTR). A single recessive mutation, the deletion of phenylalanine 508 (ΔF508), causes severe CF and resides on 70% of mutant chromosomes. Severe CF is also caused by premature stop mutations, which are found on 5% of CF chromosomes. Here we report that two common, disease–associated stop mutations can be suppressed by treating cells with low doses of the aminoglycoside antibiotic G–418. Aminoglycoside treatment resulted in the expression of full–length CFTR and restored its cyclic AMP–activated chloride channel activity. Another aminoglycoside, gentamicin, also promoted the expression of full–length CFTR. These results suggest that treatment with aminoglycosides may provide a means of restoring CFTR function in CF patients with this class of mutation.

http://tinyurl.com/ya6pjvd

Activity of the new cephalosporin CXA-101 (FR264205) against *Pseudomonas aeruginosa* isolates from chronically-infected cystic fibrosis patients. L. Zamorano, C. Juan, A. Fernández-Olmos, Y. Ge, R. Cantón and A. Oliver. Clinical Microbiology and Infection. Published Online: 16 Feb 2010

Chronic respiratory infection caused by *Pseudomonas aeruginosa* is the main driver of morbidity and mortality in cystic fibrosis (CF) patients. The development of resistance to all available antibiotics is a frequent outcome of these infections. The present study aimed to evaluate the activity of the new cephalosporin CXA-101 (FR264205) against a collection of 100 isolates obtained from 50 CF patients from two Spanish hospitals. 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. Therefore, CXA-101 is envisaged as a valuable alternative for the treatment of chronic respiratory infection caused by *P. aeruginosa* in CF patients.

http://tinyurl.com/ydpt4rz

Treatment of early Pseudomonas aeruginosa infection in patients with cystic fibrosis: the ELITE trial. Ratjen F, Munck A, Kho P, Angyalosi G. Thorax. 2009 Dec 8

Antibiotic therapy for early Pseudomonas aeruginosa infection in patients with cystic fibrosis (CF) is effective, but the optimal therapeutic regimen and duration for early treatment remains unclear. The EarLy Inhaled Tobramycin for Eradication (ELITE) study was designed to assess the efficacy and safety of two regimens (28 and 56 days) of tobramycin inhalation solution (TIS) 300 mg/5 mL (TOBI(R)) twice daily for the treatment of early onset P. aeruginosa infection in CF patients. The median time to recurrence of P. aeruginosa (any strain) was similar between the two groups. In total, 93% and 92% of the patients were free of P. aeruginosa infection one month after the end of treatment and 66% and 69% remained free after 27 months in the 28-day and 56-day groups, respectively. TIS was well tolerated. Treatment with TIS for 28 days is an effective and well tolerated therapy for early P. aeruginosa infection in CF patients.

Continued on page 31

Mailbox

Thank you for this great newsletter. It's the highlight of my day.

Aileen
Brooklyn, NY

Congratulations and deepest thanks to all at USACFA for your ongoing, extraordinary efforts on behalf of the entire CF family.

Phyllis Kossoff
New York, NY

CYSTIC FIBROSIS RESEARCH, INC.

23rd National Cystic Fibrosis Family Education Conference
July 30 - August 1, 2010

Cystic Fibrosis Research, Inc. (CFRI) presents their 23rd annual education conference. The focus is: "Quest for Better Health: Whatever it Takes". The conference will be at the Sofitel Hotel San Francisco Bay in Redwood City, California on July 30 - August 1, 2010

Speakers Include:

Eric W. Alton, M.D., F.R.C.P., Imperial College, London, UK ***"From the UK - Leading a New Era in CF Gene Therapy",*** Christopher H. Goss, M.D., University of Washington, Seattle, WA, ***"Can CF Lung Damage be Controlled - Even Prevented?",*** Robert J. Kuhn, Pharm.D., Kentucky Children's Hospital, Lexington, KY ***"Making Wise Drug Choices",*** Mark R.Weatherly, M.D., Arnold Palmer Children's Hospital, Orlando, FL ***"Choosing CF as a Doctor and a Parent",*** Mary Massery, P.T., D.P.T., Cardiovascular and Pulmonary PT, Glenview, IL ***"Practical Treatments for Posture and Pain",*** Damien Wilson, LCSW, University of Wisconsin, Madison, WI ***"Strengthening Couples When There is a Loved One with CF",*** Noreen Henig, MD of Gilead Sciences, Inc. and Delma Broussard, M.D., Eurand Pharmaceuticals ***"Success of the Quest: Newest FDA Approved Drugs".***

For more information, contact CFRI at (650) 404-9975 • cfri@cfri.org • www.CFRI.org

Cystic Fibrosis Annual Day Retreat – Must See TV: CF in Hi-Def!
August 3 - August 9, 2010

The retreat is designed to provide a safe and welcoming environment aimed at enhancing positive coping skills, social support and education for people who share common experiences with CF.

Daytime recreational activities include sports events, arts and crafts, swimming and hiking, inspired by a TV theme. Psychosocial activities will take place daily including rap sessions that specifically target teen and adult issues. The retreat will also sponsor educational workshops on self-care, CF medical interventions and other related topics. The retreat provides three high calorie meals a day. Snacks are provided as well.

Overnight accommodations are available at the Vallombrosa Center, but must be booked individually. A list of local hotels is also available. We require that people with CF stay in individual rooms with private baths, which only a non-CF person may share. Vallombrosa Center is located in a secluded area of Menlo Park, California, just minutes away from Stanford Hospital.

Any adult who has CF* may attend. Teens with CF* who are 15 – 19 may attend provided a parent or guardian accompanies them. (*Must have recent sputum cultures approved by their own CF physicians.) The retreat also welcomes health care professionals, non-CF siblings of people with CF, friends, family members, and anyone else interested in attending this very special community event. All visitors must have a retreat attendee sponsor.

CFRI encourages all persons with CF to attend the day retreat, even if you can't attend all six days. You will long remember this rewarding experience. You will learn new ways to manage cystic fibrosis and share your experiences with peers who truly understand. You will establish friendships which will last a lifetime, ones that will guide you through the rest of your journey living with cystic fibrosis.

For more information, contact: Cystic Fibrosis Research, Inc., 2672 Bayshore Parkway, Suite 520, Mountain View, CA 94043. Telephone: (650) 404-9975. Fax: (650) 404-9981. Email: mconvento@cfri.org. Website: www.cfri.org

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- Please let us know of the major occurrences in your life (*e.g.*, *marriages*, *births*, *completion of educational degrees or training*, *career advancement*, *transplants*, *anniversaries*, *birthdays*) and we will print your information in **Milestones**.
- Share your ideas for **Focus Topics**, feature articles or any suggestions for improvements you may have to help make *CF Roundtable* more relevant and interesting to you.
- You can reach **USACFA** and ***CF Roundtable*** at anytime by phone or fax at **(503)669-3561**. (That number always answers by machine.) You may email us at **cfroundtable@usacfa.org**
- Send your questions of a general nature regarding legal issues that relate to CF to our legal advisor: **Beth Sufian, Esq., 811 Rusk Street, Suite 712, Houston, TX 77002-2807**.

TILLMAN *continued from page 29*

http://tinyurl.com/yctygd2

OSTEOPOROSIS

Osteoclast function, bone turnover and inflammatory cytokines during infective exacerbations of cystic fibrosis. Elizabeth F. Shead, Charles S. Haworth, Helen Barker, Diana Bilton, Juliet E. Compst. Journal of Cystic Fibrosis.Volume 9, Issue 2, Pages 93-98 (March 2010)

Raised levels of pro-inflammatory, pro-resorptive cytokines during pulmonary infection may contribute to osteoporosis in cystic fibrosis (CF). In this study osteoclast number and activity during infective exacerbations were assessed and their relationship to serum inflammatory cytokines and bone turnover markers were examined. It was concluded that the systemic response to infection is associated with increased bone resorptive activity in patients with CF.

http://tinyurl.com/yb44762 ▲

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

HOW TO KEEP YOUR SUBSCRIPTION UP TO DATE

Do you wonder when your *CF Roundtable* subscription is due for renewal? Have you wondered how to tell if it is time to renew? Look at your mailing label. Immediately after your name, there should be a date. That is your renewal date. (On the example, you can see that Kathy is due to renew her subscription in May 2010.) If there is no date or it says (COMP COPY), your subscription is due for renewal.

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The Partnership for Prescription Assistance brings together America's pharmaceutical companies, doctors, other health care providers, patient advocacy organizations and community groups to help qualifying patients without prescription drug coverage get free or low-cost medicines through the public or private program that's right for them.

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

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

American Organ Transplant Association (AOTA): Phone: 1-713-344-2402 http://aotaonline.org/default.aspx
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