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

CF...and Breast Cancer?

By Susie Baldwin

Recently, the US Preventive Services Task Force (USPSTF), which routinely assesses the evidence base for the use of various preventive health services and activities, advised against teaching patients self breast exam. The evidence for doing self exam has never been strong, but among many clinicians it's generally been accepted that it's good for women to be familiar with their own breasts, so they have an opportunity to identify any changes that potentially could reflect malignant growth.

I was never too big on doing breast exams on myself, not so much because of the lack of evidence that such exams are helpful (or evidence that they are harmful), but because I always figured that the chances of me getting breast cancer, especially as a "young" (pre-menopausal) woman without any known risk factors, were so slim that I didn't need to worry about it. I mean, who's heard of a CF patient getting breast cancer?

SUSIE BALDWIN

It turns out, nobody, at least not in the US, Canada, or Europe. I now have the dubious distinction of being the first known CF patient to develop this disease, which greatly increases in incidence as women age. As we CF patients continue to age beyond expectations, living decades longer than doctors told our parents we could, undoubtedly more and more of us will develop co-morbidities (additional diseases) not previously seen in CF patients. *(However, I still find it hard to believe that there isn't someone else out there who has previously had breast cancer—so if you are out there, please let me know!)*

In any case, it turned out that a self-exam, of sorts, identified my tumor. Sitting on the couch watching TV the night of December 20, one year ago, I impulsively palpated with one finger the outer underside of my left breast. Under my fingertip was a prominent, mobile lump, about a centimeter in size. It hurt when I pushed on it. "Oh, I must have a cyst," I thought.

I e-mailed my primary care physician and she ordered a diagnostic mammogram and an ultrasound right away. I'd previously had a screening mammogram, when I'd turned 40 in April of 2007, which was normal. (As of November 2009, the USPSTF no longer recommends routine mammography for women in their 40s.) The breast center squeezed me in (pun intended) for an appointment

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CF ROUNDTABLE
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EDITOR'S NOTES

Happy and healthy new year to all! As 2010 begins, the U.S. has been experiencing frigid temperatures from Seattle to Florida. Remember to bundle up and ask your doctor about a second flu shot.

Note the new addresses in "Important Changes" on page 3. Please remember to send all correspondence that does not include money to our old address in Oregon, and any donations or subscriptions to the new Virginia address. We appreciate your help with this.

We have received articles from people who may have been discouraged that their writings were not published. The newsletter space is for articles that deal with adults who have CF, their lives and the issues that affect them. We give priority to articles that are written by adults who have CF. We encourage all writers, but submissions must stay within the parameters of adult issues.

Please be sure to read our cover story by **Susie Baldwin,** who had a rare experience with breast cancer. As people with CF live longer, cancer might be a more common issue than was once believed. In "Ask the Attorney", **Beth Sufian** answers questions regarding long-term disability (LTD) and SSDI. In "Spirit Medicine", **Isa Stenzel Byrnes** writes about the spirit of empathy she observed during her month-long trip to Japan. **Laura Tillman** once again gathers "Information from the Internet" with many hopeful news releases.

Our Focus topic is: "Diet and Nutrition" and we have articles by **Colleen Adamson, Andrea Eisenman, Jeanie Hanley** and **Rob Massopust.** In "Speeding Past 50", **Kathy Russell** writes about cooking tips, making leftovers fresh and balancing foods. **Julie Desch,** in "Wellness", writes about being mindful of the food that one eats while promoting healthier eating. **Paul Feld** discusses the ups and downs of eating well with CF and lung transplant, in "Transplant Talk". In "A Deep Breath In", **Debbie Ajini** looks back on her love/hate relationship with food and trying to gain weight. **Rich DeNagel** interviewed **Michelle Compton** for "Unplugged".

Read the overview of the NACFC, a review of "A Path Less Conventional" – a book by **Michael E Morrison,** and "Voices From The Roundtable", where long-time subscriber **Johanna Libbert** writes about her life and how it inspired her niece. Also check out page 34 for information from CFRI.

As we look forward to spring and renewal, please look at our future Focus topics on page 3 and consider writing for *CF Roundtable*. Until then, stay well and happy.

Andrea Eisenman

Publication of *CF Roundtable* is made possible by donations from our readers and grants from The Boomer Esiason Foundation, CF Services, and Genentech, Inc.

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

Valerie Vandervort
Verdigris, OK
38 on January 8, 2010

Lois Weisenbacher
Hampton Bays, NY
63 on December 14, 2009

Wedding

Johanna & Philip Libbert
Richland, IN
20 years on April 8, 2009

Anne & Jon Williman
Middletown, OH
35 years on August 31, 2009

Marjorie & Daniel Winokur
New Hyde Park, NY
34 years on November 22, 2009

Transplant

Marjorie Winokur, 57
New Hyde Park, NY
Bilateral lungs
5 years on December 15, 2009

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.**

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:

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Winter (current) 2010: Diet and Nutrition.
Spring (May) 2010: Traveling For Work or Pleasure With CF. (Submissions due March 15, 2010) Traveling with CF can be a hassle. Have you learned any techniques to make travel easier? Do you have any suggestions for our readers? Please share your good ideas with us.
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.)

ASK THE ATTORNEY

Questions from Readers

By Beth Sufian, Esq.

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

1. I applied for long term disability ("LTD") from my employer and was granted benefits two years ago. Recently, the LTD insurance company called my physician and asked if he thought I could return to work. My doctor said I could return to light duty work. The LTD company has sent me a letter indicating I am no longer eligible for LTD benefits. The problem is I must spend most of the day taking care of myself. Even though I would love to return to work, I cannot return to work and maintain my health. The reason I stopped work in the first place was to have time to do my treatments. I have been able to avoid being placed on a transplant list because I stopped work and was able to take better care of myself which improved my health. What can I do to keep my LTD benefits?

BETH SUFIAN

First, this question has been asked by 15 readers in the past three months from different parts of the country. The question as written is a compilation of those questions. This indicates that some physicians do not understand LTD benefit eligibility criteria. The fact that this question has been asked so many times raises a red flag. People with CF need to do a better job of making sure their physicians understand that in order to continue receiving LTD benefits the physician must indicate on any paperwork from the LTD company or in any conversations on the phone with the LTD company that their patient is not able to work full time. Saying a patient can work "light duty" is saying the patient can work full time. Whether it is light duty, medium duty or heavy duty, indicating the person can work full time almost always equals denial of LTD benefits. Therefore, it is crucial that anyone with CF who receives LTD benefits discuss the criteria for obtaining or staying on LTD benefits with their physician and CF Care Center staff. Discussing the criteria ahead of time with your physician and CF Care Center staff will increase the likelihood the physician or her staff will provide the correct information to the LTD company if called.

Second, people with CF should understand that employers do not have to offer LTD benefits to employees. Some large employers offer LTD benefits to all employees and there is no medical exam or medical exclusion criteria to be eligible for benefits. There is no federal law requiring employers to provide LTD benefits to employees. Many people with CF work for employers who do not provide LTD benefits. It is almost impossible to purchase your own independent LTD policy because the insurance companies do not have a legal obligation to sell an LTD policy to a person with a medical condition, such as CF. Once you become eligible for LTD benefits and are receiving benefits under the LTD policy, even if the employer stops providing the benefit to other employees, you will continue to receive LTD benefits. Most LTD benefit plans provide that once you are eligible to receive LTD benefits you do not need to pay the monthly LTD premium. However, if you need to pay the premium in order to keep the policy in force, make sure you pay the premium. Failure to pay the premium will result in cancellation of the policy.

Third, it is so important to make sure that your physician understands

that in order for you to receive LTD benefits from the insurance company, she must provide information indicating that you are unable to work full time because of your medical condition. If a physician indicates a patient can work light duty then the physician is indicating the person can work and the LTD benefits will stop. In a situation where the physician has made a mistake and indicated the patient can work full time when the physician does not think the patient can, the physician will need to write a letter to the LTD company indicating he made a mistake. The letter will need to indicate that it is his medical opinion that the patient cannot work full time due to his medical condition. Even with such a letter the LTD company may resist reinstating benefits because the physician had previously indicated the patient could work.

The LTD policy should have a process the policyholder can follow to appeal the denial of benefits. There is typically a time limit to file an appeal. A person whose benefits have been stopped must appeal within the time frame set out in the policy. Generally, if the person's benefits have stopped due to a physician stating the person with CF can work, then the appeal should contain a written statement from the physician indicating his earlier statement about ability to work was wrong and he was mistaken and it is his medical opinion that the person cannot work due to his medical condition. Without such a written statement, it is unlikely the person with CF will win the appeal. If documentation from the physician is submitted and the appeal is denied there may be the ability to file a second internal appeal. If there is not another internal appeal then the person has the right to file a lawsuit under the federal law, ERISA, the Employee Retirement Income Security Act. Disputes regarding employee benefits (benefits provided by an employer), such as LTD benefits, are governed by ERISA. There are very few attorneys who handle ERISA cases and it is expensive to bring a lawsuit in federal court. That is why it is so important to make sure your treating physician and CF Center understand how to complete LTD paperwork or how to respond to phone inquires about your ability to work full time. It is much easier to have the paperwork completed correctly than to go through an internal appeal or bring a lawsuit under ERISA in Federal court.

2. Can I receive unemployment benefit compensation while waiting for my Social Security Disability Insurance application to be processed by SSA?

A person who applies for and receives unemployment benefits is representing to the Unemployment Agency that the person is actively looking for full time work. A person who applies for Social Security Disability Insurance (SSDI) benefits is representing to a Federal agency that the person is not able to work full time due to their medical condition. Therefore, it is a conflict to represent that a person is able to work full time to one agency and represent to another agency that the person is not able to work full time. Penalties for misrepresenting a person's ability to work to either agency could include repayment of any funds paid to the person in the form of unemployment benefits or in the form of SSDI benefits. In addition, the Social Security Administration may find that when the person represented he could work in order to receive unemployment benefits he was not telling the truth on his application for SSDI benefits when he said he could not work. Therefore, the person may be held to be ineligible for SSDI benefits.

Some people feel they need to lie to the unemployment agency about their ability to work because they will not have enough funds to support themselves while they wait to receive SSDI benefits. It is very important for people with CF to SAVE MONEY while they are able to work. In the event the person becomes unable to work the person will need five months of living expenses. This is because SSDI has a 5-month waiting period before benefits start, even after the person's application for benefits is approved. A person who is eligible for SSDI will NEVER receive benefits for the first five months she is unable to work. I know many CF Care Centers suggest their patients save money in the event they become unable to work. I understand it is hard to accept the idea that you may be unable to work in the future. However, anyone can become unable to work due to a medical condition. Everyone, even people without CF, should also have five months of living expenses in savings in the event they become unable to work.

If you have not worked long enough to be eligible for SSDI benefits you may be eligible for SSI benefits if you meet certain low income criteria. SSI is different from SSDI. If the SSI application is approved, benefits start. SSI does not have a 5-month waiting period. Often people confuse SSI and SSDI. SSI is for people who are low income. SSDI does not consider the assets of the person applying for benefits or those of their families. ▲

Beth is 44 and has CF. She is a Director of USACFA. Her contact information is on page 2. You may send CF-related questions of a legal nature to: bsufian@usacfa.org.

SPIRIT MEDICINE

The Spirit of Empathy

By Isabel Stenzel Byrnes

Recently I returned from an amazing month-long book tour to Japan, where my twin Ana and I were privileged to advocate for cystic fibrosis and organ donation awareness.

On our first day off in two weeks, we visited Nara, the ancient capital of Japan near Kyoto. We toured old Buddhist temples, and admired orange-colored Japanese Shinto shrines and five-story pagodas. The spiritual atmosphere invited calm, so we could reflect on the blessing of this opportunity, and give thanks.

In one temple on a hill overlooking the city, I came upon a large caldron of ash with sticks of incense poked into the ash, burning and releasing smoke in ribbon-like threads. The sound of chanting was heard inside the temple, with an occasional gong. Following tradition, my mother, who joined us on part of the trip, stood by the caldron, waving her hand above the smoke, upwards, towards herself. When the smoke encircles you, it carries healing vibes and positive energy for life. An older Japanese man approached the smoky caldron just as I did. Immediately, he started to grab the rising smoke with his hand and wave it gently in my direction. He smiled and nodded shyly, offering, *"Dozo, dozo."* which means, "Here, here, for you." This stranger offered me goodness: his goodness.

This unknown man in a distant land gave me something powerful: his ability to feel for my well-being. This story introduces the theme of this article in one word: empathy.

What is empathy? Empathy is the ability to understand and relate to someone else. An empathetic person reaches outside herself, connects or engages in a meaningful, selfless way with others. Empathy evolved because our ancestor's survival in a group depended on cooperation. Over time, all spiritual traditions developed a common tenet of what we call "The Golden Rule" - treat others how you wish to be treated. Aside from a small number of people with mental disorders, I would like to believe that empathy proves that we all have the capacity to carry unlimited love (some might call it holy spirit, divinity, God, altruism, mitzvah) inside of each of us. When we empathize, we release that.

Giving and receiving empathy is a spiritual act. *It gets us outside of ourselves and places us in touch with another's humanity*. How refreshing! Empathy is spiritually healing. You even feel it, right in the middle of your chest. When someone "gets you", you glow. When you offer understanding to someone else, you "get them"; it gives you a warm and fuzzy feeling.

> *"Empathy is spiritually healing. You even feel it, right in the middle of your chest. When someone 'gets you', you glow."*

How does having cystic fibrosis affect our empathy? I believe that living with CF gives our lives an opportunity to experience heightened empathy. Most of the time, people with CF are lucky to be in a position to receive empathy - just because of our diagnosis. Our disease is genetic, it is fatal, it affects children; there is no stigma attached to it. The result is that most people's heart strings are tugged when they hear I have CF and the vast majority have responded in a compassionate manner. Those who haven't have taught me how to assert myself and respond to apathy or disrespect.

HATSUKO ARIMA (ISA'S MOM) AND ISABEL STENZEL BYRNES IN NARA, JAPAN.

For me, having CF was good upbringing. I couldn't help it when I inconvenienced people with my coughing, therapy, hospital stays, or costly medications. Yet my parents, friends, siblings and partner showed patience and offers of assistance when it was needed. I was showered with gentle nurses, strangers who listened and camp counselors who gave their time to help people with CF live a good life. These people modeled to me what it meant to feel compassion and empathize with people struggling with a challenge; in my case - CF. My predicament gave people in my life an opportunity to practice empathy, and to feel a spirit of satisfaction with their goodness. Of course, once in a while, I did not experience an empathetic person. A run-in with a rude doctor, for example, used to cause deep scars, but now I try to feel compassion for that person because there always is a story behind the behavior.

Not everyone with CF may feel that they are cared for or recipients of compassion. CF causes such complicated feelings, along with regular life, that there is the potential that a person with CF can be so frustrated with her situation that she reacts and pushes away compassion. For me, I have had to be in the right emotional place to *see* the empathy.

So often I get calls from CF friends with the dreaded words, "I'm in the hospital." I hear it, feel it, and share the disappointment. It feels good to be there for the friend and feel the shared pain. I call that a love-tug. Also, with a good friend, there is hidden agreement that when our roles are reversed she will be there to empathize with me. Empathy doesn't mean trying to save the person from her troubles. It means being a witness to that person's story. Empathy is feeling - shared on an equal plane. It is not sympathy, where someone above you feels sorry for you, in a patronizing way, because you have CF.

During my trip to Japan, for the first time in my life, I met Japanese families with loved ones with cystic fibrosis. The mothers looked just like my mother, so I embraced them like family. Tragically, in this wealthy, scientifically advanced country, the 37 registered CF patients in Japan do not have access to the medications we have in the US or Europe; therefore, the median life expectancy is only 15 years. CF is so rare in Japan that there are no specialists or non-profit organizations to help raise money. Ana and I spoke at the first charity concert fundraiser for a newly established Committee to Enable CF Treatment. Up on the screen flashed photos of one Japanese CF patient: scrawny, pale, barrel-chested, breathing heavily - just like the American CF kids in fundraising brochures from the 1970s.

A wave of emotion overcame me. Suddenly, it seemed that the spirits of all the people in my life who empathized with my struggle with CF resurfaced with a gut-wrenching ache, and I redeemed the feelings back to this Japanese CF child. I was moved to trembling and tears. I remembered how horrible this disease is, when left untreated. I felt, *"That could be me."*

It was pure chance that I was born in the United States, where we have ridden the wave of technology and reaped the benefits of Ultrase MT20®, Pulmozyme® and TOBI®. Now, in the U.S., we have big pharmaceutical companies supporting the CF community; we have the CF Foundation Pipeline; we have hundreds of online resources for CF. There is a momentum that is a life-force in our lives. It has been so long since the American CF community has been hopeless.

I felt saddened by the inequity of access to CF medication. It wasn't fair that the pictures of CF patients in my upcoming slideshow were smiling, happy, even plump adults, including some USACFA members. All of this progress has been made because so many Americans have empathized with the cruelty of this disease.

Life in the USA with CF isn't easy. This disease causes so much physical and emotional pain here, too. Not every CF patient has access to the medications she needs. Not every American CF patient is doing well. Yet seeing the CF patients in Japan offered perspective that it could be worse. We are so lucky to be Americans. We are lucky that half of us will live to be over 37 years. We are lucky to have a robust CF community. During the presentation, I cried because I remembered when I was ten years old, no one knew the name of my disease, nor its symptoms, and I knew only one other person with this strange condition. It was an unbearable loneliness. I didn't know much about my sickness that affected every one of my breaths. I was unaware of CF research but had the innate knowledge that I'd die from this disease. That is what that child on the screen was going through.

The situation in Japan mimics that of CF patients in other parts of the globe: Central and South America, Eastern Europe, other parts of Asia and even Africa. I feel helpless, because we Americans can't do a whole lot to change the situation. I dare say that some of these countries have such large populations that, "Does saving CF kids matter?" Of course it does. Every life is as important as yours and mine. Parents just like yours and mine feel the anguish of losing their kids.

My transplanted friend's life motto is, "Pay it forward." He tries to give back to society because of the gift of

Continued on page 19

SPEEDING PAST 50...
The Balance of Food

By Kathy Russell

Autumn is fast coming to an end. It has been a beautiful season, with glorious colors on the leaves and brilliant blue skies on many days. Last week we still could go out without a coat. Now, the weather is starting to turn colder. There was frost on the grass this morning. That means it is time for stews and hearty soups. (My, doesn't that fit nicely into the Focus topic of this issue: "Diet and Nutrition"?)

I love the thick soups and stews that are so comforting in the cooler weather. I especially like the fact that I can cook something once and have main dishes for more than one meal. I am very lucky to have a husband who likes these meals, too.

When planning meals, I try to think of things that will be good the first time and still will be new and different the second time. Let me explain. Many people say that they "…don't like leftovers". I can understand that. Having the same thing, over and over, could get quite boring. If one plans carefully, it is possible to make each successive use of a food seem like a new meal. I call them "planned overs".

A good example of a planned over is my clam chowder. The first time, it is plain chowder (since we try to avoid unnecessary fat, it is made without any dairy product) and is delicious. The next time, to vary it, I may add tomatoes to it and make it more of a Manhattan type of chowder. I may even split it, after the first meal, and make both chowder with milk added and Manhattan style. Each of these types has a unique taste and seems like a new soup. It takes only one time of preparing the veggies and other ingredients to make three meals.

I do similar things with pastas. When cooking most pastas, I cook enough for two meals. I put the "extra" in a container in the refrigerator and have that for another meal. I figure that everything that I can do to make meal preparation easier will help to ensure that we eat properly, when I don't feel up to cooking.

I roast a chicken most Sundays. This gives us a great Sunday dinner and chicken that is ready to use for other things later in the week. I also make stock from the bones and trimmings. That way we have soup for the week, for our lunches. The best thing about making stock is that we know exactly what is in it. We aren't getting any preservatives or additives (we have tried to avoid such things for many decades) and we get excellent flavored soup. I add a few veggies or some leftover pasta or rice and I'm done. Yum! Yum!

KATHY RUSSELL

Since I was a little girl, I have tried to avoid fat in my diet. There are two reasons for this. The first is that I don't like the "taste" of most fats and the second is that fats always have caused me intestinal discomfort. I prefer to eat more poultry and fish than red meats. When I do eat red meats (or any meats, for that matter) I try to remove as much fat as I can. (I remove the fat from my chicken stock, too.) I use a pan spray to keep foods from sticking in my cookware and find that to be quite acceptable. Even when I stir-fry, I use only sunflower or grape seed oil. Neither of those seems to bother me and they do a very nice job. I am able to tolerate extra virgin olive oil, too.

I love using my crock pot for cooking in the cooler months. A couple of years ago, we purchased a larger (six quart) crock pot and it is great for cooking things that we like to have for more than one meal. These are things such as pot roast, corned beef and cabbage, pork and sauerkraut, beef stew, bean or pea soups, chicken with rice, and the list goes on. There is room enough in the pot to cook lots of vegetables with our stews and corned beef. We both like lots of celery, carrots and onions in those things. The pot has room enough for servings for two or three meals. When I make chili, I make enough to freeze in containers for later. It is so nice to be able to take a brick of chili out of the freezer, thaw it in the microwave and serve it hot, in very little time. (And when I am not feeling well, time of preparation and ease of service are important.)

For much of my life I have thought of food as I think of my meds and treatments; it is an essential for my well-being and I have to eat, even when I am not interested in food. I know that I need nutrients to keep healthy. I never have been a big eater of sweets. I always have preferred salty and tart over sweet foods. Now, since I have compromised senses of taste and smell, I find that I like foods that have a little more spice to them than I used to. I love to add a little vinegar (either balsamic, rice or wine-flavored types of vinegar) to some dishes. I add a little pepper oil or jalapeno Tabasco sauce to other types of foods. This adds the zing to make it palatable to me. Depending on the type of food that I am cooking, I may season the entire dish or I may season only my own servings. I don't want to make it unpalatable to Paul (my husband).

Since I have high blood pressure and try to control the amount of salt that I eat, I use Mediterranean sea salt instead of table salt. The sea salt has a saltier flavor than regular salt, so I use less and still am satisfied.

I know that many people who have CF have to fight a lifelong battle to keep a good weight. Most of those people are trying to keep their weight up. Many of us are fighting to keep our weight down, while still getting adequate nutrition. I do not know which is the harder battle nor even if it can be measured. I know only that I have had to be aware of my weight for almost my entire life.

I am overweight and not too unhappy about it. I know that I have that "extra cushion" of weight that can keep me from getting too ill when I get sick, have a fever and lose weight. I have lost as much as 30 pounds in a very short time, when I had a high fever that could not be controlled. At that time, I was not overweight and it took me a long time to recover from that illness.

When I was younger, my CF physician always wanted me to carry about 20 extra pounds. Back then, I just couldn't gain that weight. (Boy! How times have changed!) I have found a type of peace with who I am and what I weigh. I never have been a "bathing beauty" and I never will be – and I am quite happy with that. I think that just being who I am and whatever size I am is okay with me.

I have friends and acquaintances who fight the "weight wars" all the time. Some are trying to gain or maintain a certain weight, while others are trying to lose or maintain another weight. Some will be successful and others will not. Family history comes into play when it comes to body size. If everyone in your family is tall and thin, chances are that you will not be plump. Conversely, if all in your family are short and stocky, you probably won't grow to be tall and thin. With that in mind, we still need to work on keeping our weight as close to what is best for us as we can. (This means with an extra few pounds for insurance.)

Having a regular eating pattern can help with weight. If we eat our meals at similar times each day, our bodies adjust to that and will better utilize our nutrients. Eating haphazardly and with little thought for the nutrient value of what we are eating can sabotage all efforts to maintain a healthy weight. If we skip meals, we may gorge when we do finally eat and that is not a good way to go. If we grab whatever junk food is lying around, we may get a feeling of satiety, but we may be getting a lot of empty calories and not many nutrients. It is important to think in terms of nutrition for the entire day. It is better for most of us to eat five or six times a day than to skip meals. Each of us should know what amount of protein, fiber and other nutrients we need each day and we should try to get it.

It is important to get not just protein. We need to eat lots of fruits and vegetables as well. I know that there was a time when CF docs were pushing the idea that people who have CF should just load up on fats and take more enzymes to deal with it. I never subscribed to that idea. If I eat fats, no matter how many enzymes I take, I will have discomfort. It is much better to eat a well-balanced diet that includes fresh fruits and veggies and lean meats. I understand that fat has lots of calories, but those are empty calories. I feel that it is far better to get good, solid calories from a good, well-balanced diet.

Many of the docs who pushed the fats also pushed sweets. They would let kids eat sweets with no thought about what that was doing to them. They failed to realize that we are prone to developing CF-related diabetes (CFRD). Pushing sugars and fats can hasten the onset of CFRD. Again, getting good, solid calories from a well-balanced diet seems to me to be the way to go.

With all that I have written here, it is important to remember that I am not a dietitian and I claim no expertise. I have only a lifetime of experience to go on. By using good food that has no preservatives and cooking mostly from scratch, I have survived very well for more than 65 years. It may take a little extra work and some planning, but it has served me well. I doubt that I would have lived this long or as well, if I had not had good nutrition. I hope that each of you can find your balance, when it comes to food. ▲

Kathy is 65 and has CF. She is a Director of USACFA. Her contact information is on page 2.

WELLNESS

Pondering Eating

By Julie Desch, M.D.

There are two things we do regarding food that are under our control. The first has to do with how we think about food, including choosing what to eat; what we "like" and "dislike." The second is how we actually ingest food.

This article stems from an interesting idea I've been reading about which is based on psycho cybernetics. The idea is that beliefs, actions, mood states and physiology are completely interrelated. They are connected in a web-like fashion such that if you change one in some way, the others can't help but change as well. The easiest of the four to intentionally modulate are beliefs and actions.

BELIEFS ABOUT FOOD

What are "beliefs" and from where do they come? Beliefs are programmed patterns of thinking based on experience, and on our memories of those experiences. I believe, for instance, that cream cheese is the most disgusting food on earth. Why? Because once, as a young adult, I ordered a pita sandwich that was STUFFED with cream cheese…and other things that I have deleted from my memory. Not heeding my intuition that this was not a good idea, I ate the whole thing. I then proceeded to be so sick for the next several days, that now I can't even look at cream cheese without being haunted by that memory. On the other hand, my son Phoenix has cream cheese on his bagel every morning and loves it. I fear for his coronary arteries already. Who has the right cream cheese belief? Whose belief is the "truth"?

The point is that these "beliefs" are simply thoughts about a particular food. Neither is true nor untrue. In the same way, if we look at our diets and really examine what we are eating and why, we might find some interesting beliefs that perhaps seemed right at one time but now make no sense at all.

One interesting exercise might be to write down everything you believe about food and its relationship to your body, tracking back to the time in your life when you had an experience that produced the belief. For instance, you may have a very strong belief that you just don't "do" vegetables. You HATE them. Always have…always will. Looking back, you realize that your first exposure to vegetables such as asparagus or green beans was dependent on a can opener. Inside were cold and wilted looking pale green tubular objects that looked and smelled nasty. So even though you now live near a weekly Farmer's Market where fresh, locally grown fruits and vegetables are available that bear no resemblance to your thoughts about green vegetables (stored memories…simply electricity flashing around in your brain), you don't even look at them. You head straight to the French fry cart.

If you can be open and flexible enough to examine your beliefs, you might find they no longer apply. Asking and answering the following questions can help with this, in addition to using a technique called "mindfulness," discussed later. As you answer the following questions, try to trace where your "belief" in your answer comes from.

> *"Mindfulness is simply present moment awareness of what is happening without judgment or manipulation."*

JULIE DESCH, MD

What feels great to eat?
What foods make you feel great after eating them?
What foods give you energy?
What foods do you hate?
What foods deplete your energy?
Knowing what you know about your body and your health, what foods do you think you could use more of?
Similarly, what foods do you think you overdo a bit?
What foods have you not tried in over five years, assuming you hate them?
If your body could talk to you, what would it say it needed?
Do you eat to fuel your body—so that it can perform what you want

it to perform? Or do you eat just to eat—out of boredom or for emotional reasons?
Do you fail to eat for similar reasons?

When you discover where these beliefs come from, ask if they still are true for you. Perhaps a Milky Way bar tasted great and gave you great energy when you studied for finals in college, but now you completely bonk an hour after ingesting one and you feel horrible. Maybe you used to eat to console yourself when worried about your health, and now that doesn't really work anymore. Maybe now, what works is a completely different approach…meditation or going for a walk or talking with a friend.

If you realize that some of your old beliefs are no longer valid, it's time to create new beliefs. Remembering that experience produces beliefs, and you have at least some control over your experience, let's look at how to create beliefs that serve your body best. One way to do this will require a little research.

Think of someone who, to you, has an ideal diet. They eat well and feel and look well as a result. What do you imagine their beliefs to be about food? Better yet, ask them what their beliefs are about food. Now, could you simply adopt those beliefs? Why not? Some experience would be needed, of course, so you would need to eat as well as they did for a while. This could seem strange, but you could do it just as an experiment. Then, you could answer the following questions about the food:

What did it feel/taste like to eat in this way?
How did I feel after I ate in this way?
What was my energy level like before and after eating in this way?
What does my body "think" about my feeding it this way?

Perhaps you may grow some new, healthy beliefs.

MINDFUL EATING

Another way to create new beliefs that are in line with current life experience is to actually *get in touch with your current life experience!* This requires a process called "mindfulness," and is one of my current favorite topics.

Mindfulness is simply present moment awareness of what is happening, without judgment or manipulation. Mindfulness of eating, therefore, would entail understanding the thoughts and emotions that go into food choice (remember, no judgment) as well as the physical, emotional, and cognitive experience of eating.

Recalling the "cybernetic loop" of belief/thought/action/physiology and how they all interact with each other, the very physical action of eating inevitably affects the other processes. The physical act of ingesting food and drink affects what you think about the foods/drinks and your mood-states that result, your beliefs about them and yourself, and the process of digestion.

Examining the way in which we eat can be somewhat startling. Do you ever just simply sit quietly and do nothing but eat? Not eat and read…or eat and talk…or eat and watch TV…or eat and drive…or eat and do a treatment (now that's tough). Can you experiment with just simply eating?

The first step in this little experiment is to determine that for one meal or snack, you are going to actually pay attention to the act of eating and to nothing else. By this, I mean noticing everything there is to notice about the food as it sits in front of you: What does it look like (colors, shapes)? What does it feel like if you are holding the food? What does it smell like? What happens in your mind and in your mouth as you imagine eating it? How does your body manage to bring the food to your mouth? As you move the food around in your mouth and chew it, what does your tongue do? As you swallow, can you feel the food going down your esophagus? Is another spoonful of food on its way to your mouth while it is still working on the previous bite?

I know this sounds strange, but what I am describing is the notion of eating *mindfully*, with awareness of everything that you sense and think as you eat, moment to moment. Taking food in this way involves intentionally seeing and smelling it first, noting its color and shape and smells and, maybe, noting what happens in your mouth as you anticipate eating; then bringing the bite to the mouth and sensing the food's texture, temperature and flavor; then slowly chewing and noting how amazing it is that your tongue and teeth are in such synchrony without any effort on your part; and finally, noticing the physical act of swallowing and sensing that the food is now one with your body.

In eating this way, the eating becomes a meditation. After a period of time of doing this practice intentionally (maybe just one snack or small meal each day or two), the act of eating changes. You tend to slow down, to chew more carefully, to enjoy and savor every moment possible as you nourish your body.

As your action of eating more mindfully changes and your beliefs about eating become more health promoting, your emotional life and physical body cannot help but become happier and healthier.

Bon appétit! ▲

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.

FOCUS TOPIC

DIET AND NUTRITION

Drink Up?

By Jeanie Hanley, MD

Returning from a party one night, I began my usual bedtime routine. I had barely started washing my face when I began coughing. The coughing became rather forceful until I felt a pop in my chest and bright red blood started gushing out. This had never happened at this magnitude and I began to panic. I yelled for my husband, John, who came running to the bathroom. At this point I was hacking into the toilet, a stream of blood following each cough. It felt like a scene from "The Exorcist", except my head wasn't spinning around.

John quickly recognized that expert medical attention was needed. As he left to call 911 he slipped and fell. Thinking that he was severely hurt, I grabbed a wad of tissues and ran over to him. In that instant, I saw that he was fine. And very soon after that, the frank bleeding began to subside. By the time the paramedics came, there was only a steady trickle. Later, I appreciated that the additional adrenaline that spiked in my system for the split second that the doctor in me believed someone else needed my help, was sufficient to put a "cork" in the bleeding vessel within my lungs.

Although that striking episode occurred 12 years ago, I remember the day clearly. I had never felt better, my PFTs had been great and there didn't seem to be any possibility of infection. I had run that morning and had been to a party that evening at a neighbor's house where we had good food and good wine. I ended up hospitalized the next day and felt a little silly because I believed I was the pillar of health. Of course, the chest x-ray proved me wrong, and so there I stayed for two weeks. As usual, once I was admitted and settled in, I slept for two days, only then comprehending how worn down I had been.

Even so, I was still a bit baffled as to what caused this profound bleeding. Was it all due to infection, or was the exercise, stress, feeling worn down or something else to blame? The bronchiectasis or damaged lung areas had clearly progressed and I wanted to understand what more I could do to slow the progression.

Over the years, and many more bleeding episodes later, I can say that many different triggers of bronchiectasis have unveiled themselves to me – some already known, such as infections (colds, pneumonia and sinusitis), inflammation (allergic bronchopulmonary aspergillosis - ABPA for short), stress and combinations of all of the above. The added instigators that took a while for me to put two and two together and to truly believe in as such were: lack of rest, strenuous exercise (once while rock climbing), too little exercise and the grand finale – alcohol.

It's the last trigger, alcohol, about which I'd like to share my thoughts with you and which took an especially long time to figure out how it affected my lungs. In contrast to the idea that alcohol (such as red wine in moderation), can be beneficial is the general knowledge that alcohol has multiple harmful health effects. Although not a heavy drinker, I do enjoy a margarita or Bailey's Irish coffee every now and then. I used to have a glass of wine or two at night several days of the week, but stopped that after making the connection to the hemoptysis (coughing up blood) from bronchiectasis.

In CF, our respiratory tract, pancreas and liver are already affected or at risk of becoming afflicted. Alcohol can adversely influence every organ system, especially these areas. Being diagnosed with CF so late, at 33 years-of-age, having a well-functioning pancreas (at the time) and fairly good lung function, I believed that I was far removed from these serious health issues with the light amount I consumed. I never considered the other side effects of one or two glasses of wine. Looking back, it's no surprise that the first episode of hemoptysis occurred right after a night where I consumed a tad more than my usual amounts.

Since then I've taken to heart how much more detrimental the intake of alcohol can be to our CF bodies. Alcoholic beverages imbibed in even small amounts interfere with many medications, rendering them less effective. They also strip away the enteric coating (protective film over a tablet that ensures slow release of medication) causing medications to be released too soon. Higher levels of the drug and increased irritation to the gut ensue.

Alcohol in moderation depresses our respiratory system, making breathing less efficient, resulting in shallow breathing with less capability of clearing our airways. The aftermath is usually felt the next day as a surge in symptoms.

Alcohol can also cause dehydration and, when consumed, can be a major reason why the hemoptysis occurs. We all have experienced dry, sometimes cracked and bleeding skin when there is low humidity in the air. When our lungs are dehydrated or

lacking their usual warm, moist environment, the airways become parched and "cracked". This occurs particularly in the areas affected by bronchiectasis, where the mucus secretions are heaviest and the airways are the most damaged and most fragile. With dehydration, these secretions are no longer loose, but become dry and strongly adherent to the dried up, weakened wall of the airway. When you are trying to cough out the mucus, it moves, taking the fragile airway wall cells with it, exposing and injuring the nearby blood vessels, causing bleeding. The larger the blood vessel injured, the greater the bleed.

Although I try to be well hydrated before and after I have that blue moon margarita, I find that when any amount of alcohol is in my system, my lungs still feel dehydrated. I could drink the Metropolitan Water District out of their water supply and wouldn't feel the moisture return to my lungs. Even so, I know I'm better off than if I didn't gulp all that water down. It often takes days for my lungs to feel recovered.

Most of the time, the risks outweigh the benefits. On occasion, if I'm feeling well, had just enough exercise, have taken all my meds and therapies, am well-rested and well-hydrated, don't have to wake up early the next day, haven't had any caffeine and know that there's little chance of inhaling tobacco smoke at the party and, basically, the stars and moon are in the best alignment, then I'll celebrate with a wee cup of Irish cheer and sip it all night, interspersed with lots of water. Or you still may find me asking for the gin and tonic, just hold the gin, please. ▲

Jeanie is 47 and has CF. She is a Director of USACFA. Her contact information is on page 2.

CLUB CF ONLINE

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

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

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

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

Announcements

VOLUNTEERS NEEDED FOR STUDIES AT NIH

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

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

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

Tips and Suggestions For Good Nutrition

By Rob Massopust

It seems some of us who have CF have a real struggle with our weight and nutrition. It is a constant battle to gain weight and keep our weight on, which is how we can stay healthy. It is obvious that the extra weight is essential to maintain our health and needed as a reserve that our bodies can rely on when we are sick. I have struggled for years with weight and health issues. It is hard to eat when you don't feel good. It takes work and energy to force feed ourselves, but it is essential to get a good grasp of what changing our eating habits and increasing our nutritional awareness can do for us.

Note: Some of the theories below may run counter to standard beliefs in the CF community. Information here is not intended to diagnose or treat illness. Patients should talk to their health care providers before stopping or changing their medical routine and they should make up their own minds and continue to do more research themselves if the suggestions here apply.

I feel that there are several areas that we should look at to improve our health that could help our bodies not work so hard against themselves. It is hard to understand and implement, but if it can make you healthier it is worth the struggle.

Blood Sugar

Unfortunately as CF adults get older the diagnosis of CF-related diabetes (CFRD) is more and more common. CFRD is difficult to accept but it is not that hard to manage with several different types of insulin. Once understood and accepted and we process the denial stage, it is just added to the "routine". Keeping our blood sugars healthy will only help to keep the rest of us healthy. Prior to a confirmed diagnosis of CFRD, I did not pay much attention to my blood sugars and I wish I had. My theory now is that with CFRD or not, CF adults should look at managing their blood sugar, understand it and monitor it. Sugar, especially in the forms most of us would eat, is not very healthy for anyone. Excess sugar is inflammatory to our lungs and causes oxidative damage. Also it is said that bacteria love sugar and they seem to feed off of too much sugar running through our systems, due to impaired glucose metabolism. I know that I had pre-diabetes way before I was diagnosed with CFRD and wish I had helped my body, instead of making it harder, by understanding the blood sugar connection.

KRISTY AND ROB MASSOPUST

(For example: just because we can drink soda (soft drinks) doesn't mean we should. Soda is a real danger to our health. Soda has empty sugar calories of the worst kind — 13 teaspoons of high fructose corn sugar. Ouch! Not to mention the highly acidic chemicals that our bodies have to neutralize. More work for our overworked systems. So be aware that empty sugar calories are hard on your body. Soda and junk food are detrimental to our health. It seems that less-refined sugars are a better choice as are natural sugar substitutes and natural fruits.)

Dairy

We are told from an early age that, "Milk does a body good." Right? But some of us might have to take a new look at this statement. Milk is full of calories and nutrition, but for those with congestion problems it might exacerbate our congestion. And with 40 million people in the US that have lactose intolerance, replacing milk might be one thing that can help your health. I try to limit my intake of milk. I use almond milk or rice milk instead. I use it on cereal, smoothies, etc. Cheese and ice cream get the green light, but I try to limit them somewhat. I noticed that every time I had a chocolate milkshake I would get real congested and started to link the two together; milk makes me more congested.

Salt

When we sweat, we flush salt out of our bodies. Supplementing with sea salt versus regular salt can help maintain our chloride levels. Sea salt is salt that is unprocessed and the original sodium and chloride molecules are intact with the necessary trace minerals that our bodies need. Regular table salt (sodium chloride) is processed at

super high temperatures and all the supporting minerals are stripped away, resulting in something that is not very healthy. So a half teaspoon of sea salt can be beneficial to us.

Water

"You're not sick; you're thirsty.", says Dr. F. Batmanghelidj. The most simple and basic substance on earth, water, is what we are sometimes missing. We need to make sure we get enough water to hydrate, flush out toxins, keep congestion loose, have ample liquid for digestive fluids and so forth.

(An amazing fact is that while we sleep, over a quart of water is evaporated by respiration. For those with lung problems, I am sure it is a larger number. It is said that asthma is not a disease but is due to dehydration. It is said that asthma results from your body's protection and conservation of its water supply, and the shutting down or constricting of this water evaporation process causes wheezy and constricted breathing.)

Try this when you wake up in the morning and feel wheezy and congested: drink 2-3 glasses of water and a ¼ teaspoon of sea salt and see if you have improvement. A good resource for more info on water and dehydration is: http://www.watercure.com.

G-Tube

If you have a G-tube and do night feeds you have an express way to gain weight. When I first got a g-tube I gained 25 lbs the first year-and-a-half. I had it for 15 years and decided to take it out. I had to get it back in, when I got really sick one time and wished I had it then to help me gain weight.

My thinking, when I did not have a g-tube, was if I could only eat more and drink more during the day, I would not need it. But the advantage is you can get one-third to one-half or more of your daily calories while you sleep. Your body is fighting all the time against infection and malabsorption, and it is almost impossible to get the extra boost of calories during the day to gain weight. This is why g-tube feedings work. I wish the prescription formulas were a little more healthful, but they are essentially to get the extra calories.

Gluten Free

If you have CF should you be gluten free? With all the challenges we have living with CF the last thing we need is "another" thing to deal with. Currently there is a deluge of health information coming out that many people have either gluten sensitivities or actual celiac disease. In the matter of CF it is an area that should be vigorously investigated, but often it falls on deaf ears.

> "We need to make sure we get enough water to hydrate, flush out toxins, keep congestion loose, have ample liquid for digestive fluids and so forth."

For me, once I found out I had celiac disease (which might be the most under-diagnosed disease out there, especially for those that have bowel and intestinal issues) it made all the difference.

I can hear you dismissively saying, "No. I don't want to know. I don't want to give up bread and pizza. Damn, not another thing to deal with." Well, maybe this will help you – good poops, sometimes perfect poops. Yeah, it is possible if you have a gluten problem and it is causing everything else in your intestines not to work. It causes physical damage. The enzymes don't work, malabsorption, low weight gain, etc. The list goes on and on. For me it was the "missing link" that I needed to improve my health. By finding out that celiac disease and/ or gluten intolerance was damaging my intestines, going gluten-free gave my intestines a necessary chance to heal and function. Your enzymes have a chance of working. You digest food and get nutrients. Looking back over the years of just poor bowel movements, loose stools and worse, I shudder to think why I did not figure this out sooner! This had such an impact on my health that I just wish I had done it sooner, obviously.

The body, and especially the CF body, is so intricately connected that when you have one system off it affects the other systems, greatly. With CF it seems like a "perfect storm"; it is amazing we are alive. But the truth is, our bodies do function, we do have some CFTR that gets through, we are able to live, and changing our diets can only help us live better. It is hard, but be proactive and make the hard choices. You only have "you" to benefit.

Some supplements that are found to be beneficial.

Magnesium – do not take with Zithromax
Zinc – helps with healing, but make sure you take with copper
Selenium – mineral that we might be missing
Taurine – helps liver and digestion
L-Glutamine – helps heal intestines
Alpha Lipoic Acid – helps oxidative stress and blood sugar issues
Vitamins A, E, K and D – fat soluble vitamins that are lacking in CF, due to malabsorption

Continued on page 21

Salt and Vinegar

By Colleen Adamson

I am addicted to salt and vinegar potato chips. I admit it. I cannot live without them; there must always be a bag or bags in the house. I get a bit nervous when I don't have a stash of them. What if I need them right away? My comfort food! I can go to the store, of course, but I can't justify that for just potato chips. In an emergency - sure. I have been eating salt and vinegar potato chips most of my life; my dad introduced them to me when I was little, and I have been chowing down ever since. What a great thing to get a person with CF hooked on - the word "salt" is even in the name! It's a no-brainer when you think of that combined with the fat content of potato chips. I wonder how many people with CF are hooked on salt and vinegar potato chips. Did other parents introduce them to their child or children with CF, because it was a great and delicious way to get their salt and fat intake? I've always wondered about that.

I love the vinegar part too – I love anything with vinegar – pickles, peppers, and pepperoncini (I will eat these until my mouth burns and then I eat some salt and vinegar potato chips to help alleviate the burning. How's that for an excellent reason to eat the chips?)

My husband is from Pennsylvania, and in Pennsylvania there are several potato chip factories – Utz, Herr's, etc. We actually went on a tour of the Herr's factory – I was in heaven! The only bad part was the sample off the conveyer belt; the chips they happened to be making at the time were the Low Salt ones - how ironic. You can imagine my disappointment; I should have told them I was coming! They tasted terrible, no offense to Herr's – I do like their salt and vinegar potato chips.

> "When I went on dialysis before my kidney transplant (in 2006), the dietitian at the dialysis facility told me I had to give up the salt. I actually cried!"

COLLEEN ADAMSON AND HER SALT & VINEGAR CHIPS.

Every time we go to my in-laws in Pennsylvania, my mother-in-law always has a bag of salt and vinegar potato chips waiting for me. Is that a great mother-in-law or what? She knows how I am about my chips by now. Also, when we are in Pennsylvania, I stock up on Pennsylvania brands of salt and vinegar potato chips; brands that I can't get down in Virginia. They are so delicious, and they taste fresher to me, I suppose, because they are made there "locally". I am serious; we always stop at a store on the way out and I get at least four bags – four bags! Talk about a serious addiction!

We have a grocery store here called Wegman's, and they make fabulous salt and vinegar potato chips that are very strong and literally burn my mouth, but I keep eating them anyway. I never eat a full bag in one sitting, but I easily could.

When I went on dialysis before my kidney transplant (in 2006), the dietitian at the dialysis facility told me I had to give up the salt. I actually cried! I didn't even cry when they told me my kidneys were failing! How silly is that? Luckily, the dietitian did research on CF diets and let me eat whatever I could to gain weight, so that was extremely helpful because not much appealed to me. She was a great dietitian – she really took the time to understand my needs and how to help bring my weight up while not getting too crazy off the dialysis diet.

I now have to cut back on my salt and vinegar potato chip eating, since I am watching my carbohydrates, cholesterol and triglycerides for the first time ever. I am weaning myself off of having them almost every night. However, as I said, the chips are my comfort food so I can still get carried away once in a while.

So there you have it – my soft spot for salt and vinegar potato chips. Don't get me wrong, I do eat my vegetables and salads with almost every meal. I do try to balance my "bad" eating obsessions with good ones. However, the scale is not quite even yet; the chips are still weighing down the scale. I'm working on it though – I just wish the chips weren't so delicious and salt-laden! ▲

Colleen is 40 and has CF. She is a Director of USACFA and is the Treasurer. Her contact information is on page 2.

LIFE-MAST

PHOTO BY STEVEN HOLLOWAY

Alveoli:
Tiny sacs, tied together
Knotted in place with muscles
Wrapped by bones
Mummified in skin
Penetrated by cystic fibrosis
Lashed fore and aft
in anger

What was I thinking, by commanding this lashing
with angry ropes to the mast of my life-ship
that I might hear death more keenly?

Why, in a rage, did I stop up the ears of my comrades
that I might hear death more keenly?
Now they can't hear me, nor I them. For they are dead.

In proud anger, I demanded the cords be drawn tighter
that I might hear death more keenly.
Now the Sirens of anger sing louder than the Sirens
of death.

Where can I flee their sinewy notes
And strive again to hear more keenly?
Oh, that's right, I can't flee. I'm bound. To the
life-mast.

Here:
penetrated by cystic fibrosis,
mummified in skin,
wrapped up by bones,
knotted in place with muscles,
tightly tied,
all the alveoli

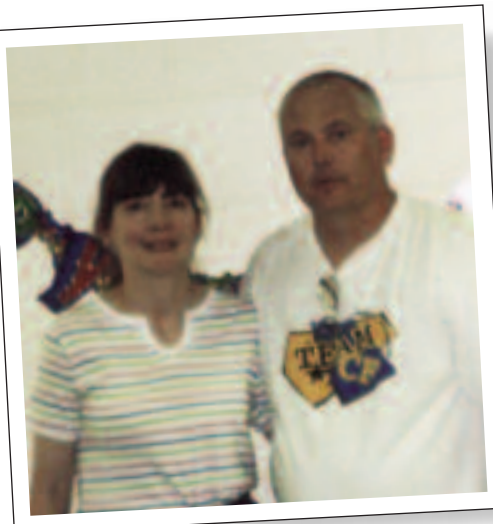
They're crowded within, fast becoming a crowd of
dead, my own Hades.
If only I had known earlier how to listen to their
melodious inspirations
and expirations.

Cynthia Dunafon
2008

"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...



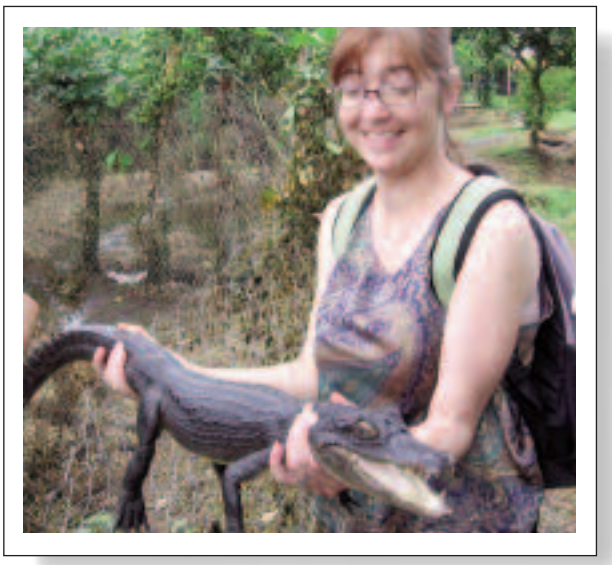
JOHANNA AND PHILIP LIBBERT.

STEVE DOWNEY AND ANDREA EISENMAN SHARE A MEAL OUT.

SUSIE BALDWIN AND HER CAT, FANGY.

JEANIE HANLEY

PAUL FELD



MICHELLE COMPTON EXAMINES THE WILD LIFE IN COSTA RICA .

BOOK REVIEW

A Path Less Conventional

By Michael E. Morrison

Reviewed by Kathy Russell

Michael Morrison is an Irish man who has CF. He has written a book, "A Path Less Conventional", about his search for alternative therapies to treat his CF. He says he has undergone research and has "come to realize that conventional Western medicine follows a chemical approach to healing that is not always effective." He adds that he has been "piecing together a complementary guide to [his] healing."

His search included visits to a "miracle man" healer, João de Jesus, in Brazil who performed invisible surgery on Michael. His description of the man and his methods is interesting, to say the least. It is hard to believe, to be blunt about it. Apparently, this miracle man gets astonishing results. Michael feels that he was helped by this man.

Another area that Michael studied is Buteyko breathing. This is a system of breathing that is supposed to make it possible for one to breathe better and more effectively. While explaining about Buteyko, he also discusses the relative benefits of the use of Himalayan crystal salt, curcumin and cayenne pepper. He gives explanations of the theory and methods of Buteyko breathing.

Michael also discusses energy, nutrition, chakras, and emotional freedom techniques. He says he hopes to give others hope about ways, other than Western medicine, to treat their problems. "I have had my ups and downs, but the decision has been mine and I hope that others reading this will learn to take control of their health and steer their way towards healing."

This book is 80 pages in softcover and is available at places such as Amazon.com.

STENZEL BYRNES *continued from page 7*

life he received. Can we, American CF adults, "Pay it forward" by helping these CF families abroad? Truthfully, many of us are so caught up in our own battles with CF that we hardly have energy to think about others' CF struggles. But one spiritual act we can offer is our empathy towards people in other countries, who are less fortunate than we are. Empathy is just that: feeling.

We don't have to do anything, but often empathy drives action. Dedicated people like those in CF Worldwide try to make an impact, but there are tremendous barriers. Ana and I, as half-Japanese, lung transplant recipients, were blessed to have the time and health to offer the little we could: education, information, signing petitions, and a limited supply of some medications (thanks to kind American CF friends). But I think the best thing we could offer the Japanese is our example: how to be patient advocates, advice on how to build community and living fully and happily with CF.

What can we do with our compassion, if we can't act? All of us can offer the universe a prayer, so that a powerful camaraderie, love and empathy shower all people with CF across the globe. Like the man at the Buddhist temple in Nara, we can wave our hands and spread the smoke of healing energy to all our fellow CF peers. This empathetic action can offer the Japanese CF patients the best medicine for the body and spirit: hope.

Feeling another's struggle means channeling the best of what makes us human and using it to connect us with others. It can give us that wonderful feeling inside, that we are good, caring, meaningful beings. This feeling is healing. I close with a favorite quote from psychologist Virginia Satir: "I believe the greatest gift I can conceive of having from anyone is to be seen, heard, understood and touched by them. The greatest gift I can give is to see, hear, understand and touch another person. When this is done, I feel contact has been made." This is the spirit medicine of empathy. ▲

Isa Stenzel Byrnes is 38 and has CF. She lives in Redwood City, CA. Email her at: thepoweroftwomovie@gmail.com if your empathy moves you to act.

An Overview of the North American Cystic Fibrosis Conference

By Rich DeNagel

This past October I had the good fortune to attend the North American Cystic Fibrosis Conference (NACFC), sponsored by the CF Foundation, in Minneapolis, Minnesota. I had heard about this conference for years and I had images of a great breakthrough being announced and celebrated. While this conference had no big celebration, there was a great amount of joy, energy and optimism in the air. Although it was not exactly what I imagined, it was an amazing event that opened my eyes to the greater world of CF and the amazing people in it.

The big news at the conference was new medications VX-770 and VX-809. These two new medications are currently in clinical trials that have shown incredible results so far. Basically, these drugs open the chloride channel, essentially fixing the basic CF defect. In the Phase I and II trials the participants showed incredible improvement in their pulmonary functions. The VX-770 works only on certain genotypes while VX-809 works on Delta F508. The VX-770 is farther along in the trials, but the researchers and the doctors are incredibly excited about this new drug. I am guardedly optimistic, but I am not ready to jump up and down and say we have found a cure. I am interested to see what happens, what side effects and what else may arise that the researchers missed.

Overall, the mood of the conference was very optimistic. Besides the VX-770 there are so many drugs in the CF pipeline: Denufosol, inhaled Aztreonam, powdered TOBI, and more. If you are not up on all the latest, go to the CF Foundation website (http://cff.org) and look on their clinical research page to see all the up and coming new medications. The horizon looks very bright with all the new clinical research piling up.

The other aspect to the conference that surprised me was the number of CF professionals and the immense dedication and devotion they have to taking care of us. I have to admit that it was a bit weird to be there, as there were only a handful of CF patients and over 3000 CF professionals, doctors, nurses, social workers, physical therapists and dietitians. Each day began at 7 am with morning discussions, and each morning the auditorium would be packed. (I heard about these events more than I made it to them. I had treatments and chest PT to do!) The day would go on until 5 pm with amazing and dynamic workshops. In each workshop I attended, it was evident how devoted and hard-working these people are for us. They always spoke about their patients and how much they wanted to help us. In the halls and vendor area there was nonstop chatter about us! It was exhausting talking about CF all day.

> “The other aspect to the conference that surprised me was the number of CF professionals and the immense dedication and devotion they have to taking care of us.”

The conference also included all the aspects you would imagine. There was an amazing vendor area with all the pharmaceutical companies, where I attempted to get as many products and goodies as I could. Unfortunately, the pharmaceutical companies are not as generous as they used to be! I also got a great satchel, from the CF Foundation, for being a participant. There were all the doctors still not having enough time for anyone, nurses chatting up everyone and the pharmaceutical reps being nice to everyone.

By the end of the conference I was exhausted. I had learned so much about the latest research and trends in CF. Everything we know about CF seems to be under the microscope. Basically they are looking at everything again; from exacerbation to enzymes to you name it. Besides that aspect there was the emotional side of it all. Mainly, I was overwhelmed by how much the people who take care *of* us care *about* us. They want us to be healthy, even more then we do, I started to think. It was amazing. I did not do justice to the entirety of the conference. The two aspects I will walk away with are the dawning of a new horizon in CF and the love the people who care for us have. ▲

Rich is 41 and has CF. He is a Director of USACFA. His contact information is on page 2.

Vitamin C and Bs – water soluble vitamins that need to be replenished daily

Some good foods to look at to gain weight.

Nuts – Good for you and full of calories. Also have carbs and protein and — lots of calories. Look for nuts that are high in Omega 3 – Almonds, walnuts, Brazil nuts (also high in selenium).

Almond and rice milk - Taste great and good for you, good alternative to milk. Note: Soy milk is not recommended because some studies show that soy is contraindicated with CF patients, meaning that the isoflavonoids in soy might have other effects.

Almond Butter – Good alternative to peanut butter, much higher in Omega 3 than peanut butter, which tends to have more Omega 6 (which can cause more inflammation).

Coconut oil – Full of calories, but the amazing thing is that coconut oil does not need to use enzymes to digest. It is an instant concentrated energy source, sparing your glucose metabolism.

MCT oil – Medium chain triglycerides (which is also coconut oil) but comes in a liquid form and available by prescription. (Also available as a product such as MCT Fuel by Twin Labs.)

Rice protein – Made from rice, good source of protein.

Whey protein – Good source of complete protein. May cause some congestion issues and lactose intolerance, in high doses.

Low glycemic carbs – Pasta, whole grains, beans - full of calories and nutrition

Protein bars – Good for on the go protein and calories

Fruit and Veggies – We need lots of fresh fruits and veggies. Don't be shy. Eat as much as possible. Your body needs the nutrients, fiber and enzymes that are found only in fresh foods.

Recipe

Almond Butter and Banana Smoothie (over 700 Calories and tastes great and is great for you).

1 Cup almond milk (regular milk can be used if tolerated well)
¼ Cup almond butter (sunflower or peanut butter can be used)
1 banana
2 Tbsp. rice or whey protein
2 Tbsp. honey
4 ice cubes
Pinch of sea salt – For electrolytes and helps the potassium in the banana
2 Tbsp. of liquid MCT oil. (Coconut oil can be used, but is solid at room temperature or lower.)
Mix in a blender and serve. ▲

Rob is 39 and has CF, CFRD and celiac disease. He and his wife, Kristy, live in Los Angeles with their dog, Dixie. His e-mail is: rmotion@yahoo.com.

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.

Cooking and Eating Well — Too Well

By Andrea Eisenman

As I sit down to write this, I have just made a marinara sauce, later to be used for making pizza and lasagna, and a big bowl of cucumber salad to be consumed soon. If I am not cooking or making food, I am thinking about it. That is partly why I am heavier than I ever have been. That, and an antidepressant called mirtazipine (Remeron® is the brand name).

It is odd, after spending the majority of my life as a 90-somethng-pound weakling, I am now about 120 lbs and a bit on the chunky side. I always liked food, but prior to transplant I could not eat too much as the food took up room in my gut that pushed into my sparse lung space. It was also unfortunate that anything fattening, such as cheeses, milk products or sweet things like ice cream or shakes, made me cough so hard that it triggered my gag-reflex and out it all came.

Post-transplant, that all changed. I loved eating again. I could eat and eat, and never threw up from coughing – I rarely coughed. I was able to slowly start gaining weight after trying to keep what I had pre-transplant. I ate sensibly – usually. I got spoiled; I could eat all I wanted and was able to maintain my weight or gain when I wanted. Then, I started to get stomachaches from eating out too much. I thought it was due to the oil used in the places I frequented. So, I started to cook at home.

I used to make the basics – baked chicken, chicken soup, pasta with sauce, lasagna. But that became boring and I yearned for more take-out. So, my therapist at the time suggested I take cooking classes at a local culinary school — not pay for classes but become a teaching assistant and learn to cook that way. I did that: it was a bit back-breaking for 5 hours and then we ate what we cooked. I received the recipes and the know-how. I also volunteered at the school's office and received time to take classes like a student – but for free. I learned knife skills and techniques to simplify kitchen work. This all gave me the confidence I lacked and I began to cook more and more complex items. I still have a few favorites that I keep in rotation once every two weeks or so.

ANDREA EISENMAN CHOPPING FOOD.

Learning to cook, or ridding myself of fear in the kitchen, helped me make tasty, healthy meals. I controlled the oils and fats and my digestion was much better. I still go out occasionally but prefer to eat at home. This also became a creative outlet for my artistic side. This has led me to go food shopping about once a week and to try to make about three different things per week that my husband and I can eat and have as leftovers. For a wedding present, my bridesmaids bestowed on us a slow-cooker, also known as a crock pot. It really is great. I just dump some meat or chicken in with onions, vegetables and some stock with some wine and like magic, a few hours later, it is dinner. Easy and yummy.

So, after all this eating, I find myself unable to lose weight. It is frustrating as I go to the gym almost every day and exercise my brains out for about one to one-and-a-half hours. I know – how can someone with CF want to lose weight when most other people who have CF want to gain? Well, it is really a control issue, I think. When I was too skinny, I would have given anything to gain 5 pounds, much to the jealousy of my friends without CF. But now my clothes are tight and I feel conscious of my girth. I know it is ridiculous to worry. My pulmonologist told me he prefers I have a few extra pounds in case I get sick. The extra weight paid off when I did get sick a few years ago. It helped me not slip back to where I once was – too thin.

The problem with the extra weight is, I don't feel attractive. It doesn't matter that others say, "You look fine." or "You look healthy!". I feel sluggish and fat, mostly in my face and stomach. One problem is that the antidepressant I take, as mentioned above, makes one put on 5-10 pounds. That was fine, when I first started taking it and I was 95 pounds, but now I have to watch every morsel I ingest. Mirtazipine works better for me than other medications I have tried and helps me sleep, too. I also have to take insulin for everything,

which probably increases my weight gain as well. Also, when I hit age 40, I noticed my metabolism slowing. So, all these things contribute to a perfect storm for weight gain.

At times I make peace with my extra weight and then I get upset after I try on something that fit only a year ago but now seems to want to split in two. I continue to cook at home and try to eat more vegetables than protein. I go for a lot of greens like kale, broccoli, spinach and orange–y squashes to get as much antioxidants as possible from my food. I try to keep the carbohydrates low for diabetes purposes as well as because they can increase weight gain. And lastly, I try to limit my portions of food, but I just love to eat and enjoy it so much that I have a hard time controlling myself.

> "I know – how can someone with CF want to lose weight when most other people who have CF want to gain?"

At the end of the day, I feel lucky to be alive. I am almost 10 years post-lung transplant and have about 10 extra pounds. But I will take it as it is better than the alternative — not being around. I get to experience what over half the American population feels about dieting and trying to lose weight. I will try to live with that burden. Bon appétit! ▲

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.

Information from the Internet...

Compiled By Laura Tillman

This issue brings a potpourri of articles from the Internet

NEWS RELEASES

Penn Study Finds that Antioxidant Found in Vegetables Has Implications for Treating Cystic Fibrosis.

Scientists have discovered that a dietary antioxidant found in such vegetables as broccoli and cauliflower protects cells from damage caused by chemicals generated during the body's inflammatory response to infection and injury. The finding has implications for such inflammation-based disorders as cystic fibrosis (CF). The antioxidant thiocyanate, normally existing in the body, protects lung cells from injuries caused by accumulations of hydrogen peroxide and hypochlorite - the active ingredient in household bleach. These potentially harmful chemicals are made by the body as a reaction to infection and injury. In addition, thiocyanate also protects cells from hypochlorite produced in reactions involving MPO, an enzyme released from germ-fighting white blood cells during inflammation.
http://tinyurl.com/yapq3rg

Eurand Launches ZENPEP(TM) (Pancrelipase) Delayed-Release Capsules

Eurand announced the commercial availability of ZENPEP™ (pancrelipase) Delayed-Release Capsules, a pancreatic enzyme product (PEP) indicated for the treatment of exocrine pancreatic insufficiency (EPI) due to cystic fibrosis (CF) or other conditions. Most patients with CF who are prescribed ZENPEP will have access to Eurand's Z-Points™, a patient-adherence program designed to support patient access to the Company's array of CF care-related items such as the TRIO® electronic nebulizer, Source CF® vitamins (specifically formulated for patients with CF), Nutra/Balance® snacks and more. The only FDA-approved PEP evaluated in clinical studies in adults and children as young as one, ZENPEP was specifically formulated to meet the FDA's guidelines and regulations for the PEP drug class. ZENPEP is also the only FDA-approved PEP offered in four dosage strengths — 5,000, 10,000, 15,000 and 20,000 units of lipase — to allow for precise dosing and for potentially reduced pill burden.
http://money.cnn.com/news/newsfeeds/articles/marketwire/0563600.htm

Genta to Support Initiation of New Clinical Trial using Ganite® as Treatment for Life-Threatining Infections in Patients with Cystic Fibrosis.

Genta Incorporated announced that the Company will supply Ganite ® (gallium nitrate injection) for a new clinical trial that will be initiated in patients with cystic fibrosis (CF) who may develop serious infections. Recent information has suggested that gallium may be used as an anti-bacterial agent against Pseudomonas, in part due to its ability to disrupt biofilms. Preliminary data suggest that gallium exploits potentially vulnerable mechanisms in Pseudomonas by disrupting

Continued on page 24

biofilms and killing antibiotic-resistant strains of bacteria.
http://tinyurl.com/yfkqyle

NanoBio`s Nanoemulsion Kills Drug-Resistant Bacteria Found in Cystic Fibrosis Patients

NanoBio Corporation today announced compelling preclinical data for NB-401, nebulized nanoemulsion-based agent that kills highly drug-resistant strains of bacteria commonly found in cystic fibrosis (CF) patients. Currently there are limited treatment options available that effectively address these resistant bacteria. NB-401 has been shown to be highly efficacious in vitro against Pseudomonas aeruginosa, Burkholderia, Acinetobacter, Stenotrophomonas and other multi-drug-resistant bacterial strains from CF patients, including colistin-resistant isolates of Burkholderia and Stenotrophomonas. In addition, the nanoemulsion is effective against organisms that are grown in biofilm and the sputum from CF patients. Resistance to the nanoemulsion is not anticipated, based on its unique mechanism of action of interacting with the bacterial membrane and causing physical lysis of the organism.
http://www.reuters.com/article/pressRelase/idUS160578+15-Oct 2009+BW20091015

BACTERIA

***Pseudomonas aeruginosa* Microevolution during Cystic Fibrosis Lung Infection Establishes Clones with Adapted Virulence.** Alessandra Bragonzi, Moira Paroni, Alessandro Nonis, Nina Cramer, Sara Montanari, Joanna Rejman, Clelia Di Serio, Gerd Döring and Burkhard Tümmler. American Journal of Respiratory and Critical Care Medicine, Vol. 180, pp.138-145, (2009)

During long-term lung infection in patients with CF, *Pseudomonas aeruginosa (Pa)* strains develop mutations leading to clonal expansion. This microevolution is believed to be correlated with a reduced virulence. The findings indicate that clonal expansion of *Pa* strains during microevolution within CF lungs leads to populations with altered but not reduced virulence. These *Pa* clones with adapted virulence play a critical role in the pathogenesis of chronic infections and may serve to define virulence determinants as targets for novel therapies.
http://ajrccm.atsjournals.org/cgi/content/abstract/180/2/138

Airway infection with a novel *Cupriavidus* species in persons with cystic fibrosis (CF). Wiltrud Maria Kalka-Moll, John J. LiPuma, Frank J. Accurso, Georg Plum, Silke van Koningsbruggen, and Peter Vandamme. J. Clin. Microbiol. Published online ahead of print.

The recovery and identification of a bacterium that represents a new species of the genus *Cupriavidus* from cultures of respiratory tract specimens from two patients with CF is described. The elucidation of the role of this species in CF lung disease will require an evaluation of a greater number of cases.
http://jcm.asm.org/cgi/content/abstract/JCM.00846-09v1

***Trichosporon mycotoxinivorans*: A Novel Respiratory Pathogen in Patients With Cystic Fibrosis.** Patrick W. Hickey, Deanna A. Sutton, Annette W. Fothergill, Michael G. Rinaldi, Brian L. Wickes, Howard J. Schmidt, and Thomas J. Walsh. J. Clin. Microbiol. Published online ahead of print on 5 August 2009

Trichosporon mycotoxinivorans is a newly recognized human pathogen that is associated with cystic fibrosis.
http://jcm.asm.org/cgi/content/abstract/JCM.00460-09v1

TREATMENTS

New clinical guidelines for exacerbations in cystic fibrosis

The committee gave guidance on two areas of significant interest to clinicians: synergy testing and the dosing of aminoglycoside antibiotics. In the case of synergy testing, it was found to have little benefit to the patient and the committee recommended against the routine use of it. In the case of aminoglycoside antibiotics, they found that three-times-daily dosing was no more effective than once-daily dosing and recommended once-daily dosing in most cases. The committee also affirmatively recommended continuation of two current practices-continuing chronic therapies during exacerbation treatment and airway clearance therapies-both of which were found to have moderate benefits to the patient. The committee found that in six of ten investigated practices, there was simply not enough data to recommend for or against them. Research is needed that would clarify whether there are different outcomes associated with the practices, which included inpatient versus outpatient care; simultaneous use of intravenous and inhaled antibiotics; number of antibiotics used to treat Pseudomonas aeruginosa; continuous infusion of betalactam antibiotics; and duration of antibiotic treatment.
http://www.medicalnewstoday.com/articles/168498.php

Vitamin D supplementation for cystic fibrosis. Ferguson JH, Chang AB. Cochrane Database of Systematic Reviews 2009, Issue 4.

Cystic fibrosis (CF) with pancreatic insufficiency can cause vitamins, such as vitamin D, to be inadequately absorbed leading to vitamin deficiencies. Lack of vitamin D (vitamin D deficiency) can cause specific problems such as bone deformity and bone fractures. It can also be associated with poorer general and respiratory health. Thus, people with CF are usually given regular vitamin D preparations from a very young age. However, excess vita-

Continued on page 29

on Christmas Eve day, for which I was very grateful. The radiologist reviewed my films immediately and discerned a mass that was suspicious for cancer. He performed the ultrasound himself and admitted (at my request) that on ultrasound, too, the mass appeared suspicious for cancer, being solid and of irregular shape. They scheduled me for a biopsy the following week. The biopsy was an extensive, terribly uncomfortable and, at times, painful procedure—the doctor took over 15 bites of tissue. I was left sore, bruised, and scared.

I was hoping I had some unusual solid benign tumor. But first thing the morning of January 2, the phone rang and I found out that my biopsy had revealed invasive ductal carcinoma of the left breast. Happy New Year! I was shocked—too shocked to even cry. Fortunately, my husband was by my side. He'd worked New Year's Eve 500 miles away, but drove home right afterwards because he was worried about how I was doing after the biopsy.

We had just been through the most difficult year of my life (our lives). I caught the flu in January 2008 (despite getting my flu shot early), and developed a devastating pneumonia. After spending most of February in the hospital – a stay which included a bronchoscopy, a few days on BiPAP, severe pain (from herniated and ruptured vertebral discs, injured from violent coughing) and extreme nausea (from a drug reaction) – I was discharged home in the worst shape I'd ever experienced in my life. I couldn't walk, I couldn't eat, and I could barely breathe. I was an invalid. I thought life as I knew it was over.

It took months to recover, but I felt like myself again by June. I emerged from the ordeal with an even greater sense of gratitude for my life, my health, and my freedom.

And then, breast cancer. I am not sure if I believe in God, but the diagnosis did seem like a cosmic joke or a grand test. It was ridiculous. But there was no way around it. All the fun things I had planned had to be put on hold—including a trip to Peru that was scheduled for March – the fulfillment of a lifelong dream. My life instead became yet another adventure through the world of health care.

I headed down the path forged by countless women before me, including some of my own patients. In many ways, it was a relief to have a disease that so many people knew about and for which treatment choices were so well-researched and understood. Colleagues and friends of friends came out of the woodwork to tell me their stories of breast cancer survivorship.

> "It turned out that a self-exam, of sorts, identified my tumor."

But my story would be a bit different. CF complicated things every step of the way. First, there was the issue of how to anesthetize me during surgery; it was dangerous to give me general anesthesia, so the surgeon performed a lumpectomy (removing a piece of the breast tissue where the tumor was) and sentinel node biopsy (checking the lymph nodes that drain from the breast) under local anesthesia with conscious sedation. Then, with tenderness of my side and chest following surgery, it was difficult to do airway clearance. Radiation therapy was a scary proposition, knowing that a sliver of my lung would be killed by the beam, and that one potential complication is radiation pneumonitis, lung inflammation that would be of minimal consequence in a healthy woman but might be grave in a CF patient. And the prospect of needing chemotherapy was terrifying—immunosuppression could threaten my life. Fortunately, a series of tests revealed that chemotherapy wasn't absolutely required for my treatment, so I was able to choose to forego it. (I still wonder about this decision, knowing that microscopic breast cancer tumor cells might be lurking within me.)

Throughout the treatment, I didn't miss much work. I didn't want to use my short-term disability insurance to take time off, because I needed to save that in case I got *really* sick with a CF exacerbation. How many people don't take time off to deal with their cancer because they're worried something *worse* could happen in the very near future? It's kind of perverse. But my cancer wasn't so bad. The tumor was small and had not spread. All in all, the treatment went pretty smoothly. Chances are, breast cancer will not be what kills me.

While I was undergoing major treatment, I didn't really deal with the emotional and mental health aspects of the cancer diagnosis. I guess I suppressed a lot of things just so I could get through it all with composure and keep up with my work. Living with CF, I've learned that sometimes a little denial (particularly about one's mortality) goes a long way towards being able to live a relatively normal life. But at the time in the disease and treatment course, when many women join a breast cancer support group, I realized that what I really needed was a CF support group. A late-night internet search led me to USACFA. Amazingly, I did not previously know that this group, or this *CF Roundtable* newsletter existed, despite my connection with an adult CF center. Finding so many other adults out there with CF has given me hope—and, I hope, a sympathetic audience for my breast cancer tale of woe. ▲

Susie is 42 and has CF. She is a physician who lives in Los Angeles, CA. She can be reached at: susie.baldwin@gmail.com.

TRANSPLANT TALK

Nutrition and Diet

By Paul Feld

I think I could write a 5000 word article on this topic as it relates to a transplanted, 52-year-old person with CF. I happen to be pretty opinionated on this topic as is my wonderful wife, Kristi, and it often is a point of contention. I suppose it's not uncommon for a non-CF person to have opposing views to a CF person, as what's good for the goose is not necessarily good for the gander.

Let's start with some basic information for CF patients. I'll stereotype a bit, but these traits are common among us CF folks. We are skinny and underweight for the most part. Most of us take enzymes to help us digest foods so they can be absorbed into our systems. We do not digest fatty foods well, at all. Our appetites tend to be heavier than normal, as we use a lot of energy while the foods we take in metabolize rather quickly. These traits are simply not true of the average adult. In addition, a transplanted CF patient has a darn good chance of having CF-related diabetes, especially immediately following transplant when dosages of rejection medications are at their highest. It's also likely that when these dosages return to their maintenance levels, blood sugars continue to be a problem and often seesaw to extremes, so they must be managed tightly.

My personal plight plays out like this. I weigh 135 pounds today. I am 5 feet, 9 inches tall. My lowest adult weight was 123 pounds, about five days post-transplant. My highest adult weight was 153 pounds, about four months post-transplant. My 153 lb. weight was a result of high doses of prednisone, enormous prednisone related appetite, and significant lack of exercise immediately post-transplant. I feel my optimal weight is about 135-140 pounds, and although I am in that range today, I don't care for the way my body has distributed that weight. I think we can all relate to that a bit. I'd certainly like to take 8-10 pounds from my stomach area and move it to my biceps and calves. I admit to doing very little in the way of weight training.

As it relates to foods, I certainly have my vices. I am sure I drink too much Mountain Dew, and not enough water. Pretzels and cookies are a couple of my favorite snack items, and I'll comfortably eat any kind of carbohydrate you put in front of me. I do like fruits and vegetables, but I don't go out of my way for them like I do carbs. I also like dairy products, including milk and cheeses, which is not so typical of CF patients, as milk tends to be problematic for those of us who cough for a living.

On the other hand, my wife, Kristi, closely watches everything she eats. She is neither heavy nor light, weighing slightly more than me at 5 feet 7 inches tall. She also wishes her weight was distributed differently. That is where we agree, while we often have challenges deciding what to eat when we are together. She is very good at eating all the right things. A good meal for her is a single carb, single fruit, a vegetable or two, a protein item, and never any liquor, wine, or soft drink. It's milk, water, or tea for her. My ideal meal is three servings of carbs, two servings of meat/fish, a single serving of fruit/vegetable, and probably a 16 ounce soft drink. And while I don't usually do dessert, I'll rob the cookie jar or candy dish within a half hour of finishing most meals. For the average person, this is a horrible way to eat, but maybe for a CF patient it fits the daily needs I have.

She and I debate this often. It's easy for her to criticize my diet. It's just not healthy to eat the way I do. However I don't gain weight, and I somehow manage to keep my blood sugars stable when on the maintenance levels of my medications, so I think it's OK. When I have tried to eat like Kristi does, I feel hungry all the time, often tired, and have less energy. So, I'll continue doing as I do with the couple of eating vices I have.

I would be remiss if I did not mention exercise. I am not crazy or fanatical about exercise. However, I'll rarely go a day without a 1-3 mile walk and some aerobic activities. Six months prior to the US Transplant games, my walks turn into jogs or running to prepare for the events I participate in during the games. These usually consist of a 5K run, 100/200 meter sprints, volleyball, and the softball throw. I rarely, if ever, win anything, but I do enjoy the competition and mostly being around my peers. I mention this only to say it's my belief that I work off most of the carbs I eat through exercise and simply having CF, which is something I cannot change. I am pretty certain if I curtailed exercise, my weight would rise and I would feel bloated and "unenergetic", like many Americans do today. So, continue to listen to my fellow Director, Julie Desch, read her Wellness section, and be OK with eating – like me! ▲

Paul is 52 and has CF. He is a Director of USACFA. His contact information is on page 2.

Voices from the Roundtable

Dear CF Roundtable,
I have always found your newsletter to be very informative as well as providing insights for all individuals with CF.

I am 43 years old and I was diagnosed when I was 9 years old. On April 8, 2009, my husband, Philip, and I celebrated our 20th wedding anniversary. I worked as a registered respiratory therapist for seven years before retiring in 1995. Since 1996, I have been drawing social security disability. I am on the brink of qualifying for a lung transplant.

As some of you know, sometimes one develops a feeling of uselessness after a while. It's always nice to find a way to feel needed. This came for me recently, by way of an invitation to speak to the nursing students at Ivy Tech College in Evansville, Indiana. I was to talk about cystic fibrosis; a patient's perspective, my routine and the impact CF has made on me and my family. I was apprehensive to speak in front of a large group and said, "No," in the beginning. But later I came to see it as an honor to be asked to serve others.

My husband videotaped my presentation, and after viewing it my niece, Rachel, wrote the most beautiful poem. My life with CF inspired her and, in turn, her lovely words can encourage, speak of understanding or give comfort. (See sidebar.)

I think we all strive to be understood no matter where we are in our life journey, with or without CF.

Love and thanks,
Johanna Libbert
Richland, IN

A Poem for Johanna

By Rachael Altmeyer

For it is in darkness
We shall find a light
That light, shall be our salvation
From the torment we have braved.

Tripped and stumbled
Fallen and cried
We are not weakened by what we survived.

We are strengthened
Strength is renewed
Renewed by loved ones
And renewed by you.

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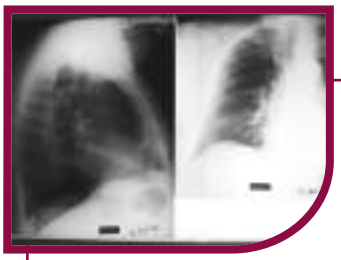

A DEEP BREATH IN
Love Thy Enemy

By Debbie Ajini

Ah, food...glorious food. Who doesn't love it?! For me, I can go either way, but when I am sick I tend toward the enemy viewpoint. While I am only mildly pancreatic insufficient, I have always had to struggle to gain weight and maintain it. I have had a love/hate relationship with eating since I was a teenager. I recall, during a time when I was quite underweight, I had a pass to eat anything I wanted at anytime during any class in high school. Sounds fun, but it really wasn't. As anyone who has needed to gain weight will tell you, if you are sick enough to lose the weight then you are also probably not really keen on the idea of eating. Yet, it is in those instances when we must eat even more than normal.

During high school, for a year at least, I put a feeding tube in my nose. I would put it in at night and my mom would help me take it out in the morning. I was a teenage rebel too — I would wear my feeding tube out in public. If I wasn't going to school, it was easier just to leave it in. Let me just say that I got a lot of looks from that!

In the fall of 1988, despite my best efforts with the nasal tube, I just wasn't gaining enough weight. So on Halloween I had a feeding tube placed (it was later converted to a Mickey button). I began using it immediately. Within three months I had gained almost 25 pounds; it was truly amazing! I didn't have to stress so much about everything I was eating and I also didn't have to bother with the mess of the nose tube. It was clear that the weight gain was helping my health as my hospital visits became fewer. I felt better, I looked better.

As a young woman, I began taking Depo Provera birth control injections. A side effect of the medication is weight gain. At first I was okay with it, but I actually did get to the point where I felt fat. I wasn't, mind you, but having been so thin all my life made it weird to be healthy plus. I did eventually decide to quit the shots because of the weight gain.

I did not use my feeding tube for most of 1997 or all of 1998, so my doctor and I agreed it was okay to remove it. I did need surgery to close the hole because scar tissue had formed. It was so nice to be free of the feeding tube. I felt I had conquered one part of CF, so to speak. I had a regular appetite again and I was able to maintain my own weight. I also was able to really enjoy food again. It became less of a chore. For the next seven years my weight was at a healthy number.

When I got really sick in 2005, I lost 20 pounds in just a couple of months. For me, as I am sure with many other adults with CF, it comes off so fast but takes much longer to get back. The good thing was that at that point I realized the value of the weight, so I knew I had to do things to get it back. Despite not wanting to eat at all, I did. I also started having a Scandishake every night. I also knew it was better for me to eat a bunch of smaller snacks all day rather than try to eat three meals. It was easier to take in 150 calories at a time than 400 or 500. Having had a feeding tube is always a reminder for me of what measures could be taken if I couldn't turn things around.

> *"I know this approach may not work for everyone but when I am sick, or really anything but my ideal weight, I look at eating as a treatment."*

A YOUNG, THIN DEBBIE AJINI.

I do wish I could, for a moment, allow my support team to feel the absolute non-interest in food that comes with an infection. It is so hard to explain. It is usually a combination of being too tired to eat, being nauseous from medication, food tasting funny due to inhaled drugs or a harder-to-name void of the desire to eat. I have talked to people with other diseases, including cancer, who have had the same experience. It is the absolute void of appetite that is hardest for people to understand. I have learned that while I may give in to the lack of appetite for a couple of days initially, I simply must NOT let it go more that that. I HAVE to eat. Often! If I lose 5 pounds from an

TILLMAN *continued from page 24*

infection, I go to work right away to gain it back. I know it is valuable in fighting the infections as well as for being ready for a transplant.

I know this approach may not work for everyone but when I am sick, or really anything but my ideal weight, I look at eating as a treatment. I enjoy food, I love going out to eat, but it has also lost some of its luster as I need the extra calories. Just last month I reached my weight goal of 140 and was happy to start maintaining it. Then last week I went on IVs and, surprise, I have lost 5 pounds. The good news is I know how to get it back, I know the value of it and I WILL do it.

The one thing that time brings us is the ability to better understand our bodies and see patterns in our health. This allows time for us to reflect and learn from the past. As I said, over the past 20 years I have come to value the need for weight and I know how to make the pounds come back. I am moving into a new phase of understanding the food I put into my body. Through this most recent battle for weight I have realized a connection between foods and how they make me feel, usually for the worse. The problem with this is that the foods that help me gain the most weight seem to make me feel bad (short of breath, more inflamed). So I have had to balance what I eat with my caloric needs. I have also learned ways to minimize the effects of the food. For me, I have found that eating sugar, certain dairy products or drinking alcohol makes me feel worse. This is something I continue to research as I find better, healthier ways to gain and maintain my weight - which I plan to share in a future column. But for now, when I need them – deep fried cheese, ice cream and candy are my friends! And if I ever need inspiration to gain weight, I just look at this photo of me, just before I had the feeding tube surgically placed. It inspires me to eat every time! ▲

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

min D can also cause respiratory problems and problems with high calcium levels. The review contains three trials, but we could extract data from only two trials. We found no evidence to show whether giving vitamin D regularly to people with CF is beneficial or not. The authors are unable to draw any conclusions regarding the routine administration of Vitamin D supplements and recommend that until further evidence is available, local guidelines are followed regarding this practice.

http://www.cochrane.org/reviews/en/ab007298.html

Pharmacokinetics and safety of tobramycin administered by the PARI eFlow® rapid nebulizer in cystic fibrosis. Dominique Huberta, Sylvie Leroyb, Raphaële Nove-Josserandc, Marlène Murris-Espind, Laurent Melye, Stéphane Dominiquef, Bertrand Delaisig, Pearl Khoh, John M Kovarik. Journal of Cystic Fibrosis. Volume 8, Issue 5, Pages 332-337 (September 2009)

In this randomized, open-label, multicentre, two-period, crossover study, patients (n=25) with CF and chronic pulmonary pseudomonal infection received TSI for 15 days via eFlow *rapid* or LC PLUS nebulizer. Nebulization times and sputum/serum tobramycin concentrations were determined, and safety evaluated. Nebulization times were significantly shorter for eFlow *rapid* versus LC PLUS on Day 1 and Day 15. Broadly comparable sputum/systemic exposure to tobramycin was observed and the incidence…

http://tinyurl.com/mumnug

Emerging treatments in cystic fibrosis. Jones AM, Helm JM. Drugs. 2009;69(14):1903-10.

There are a number of potential drugs for the treatment of cystic fibrosis (CF) currently undergoing clinical studies. A number of antibacterials formulated for delivery by inhalation are at various stages of study; these include dry-powder inhaler versions of colistin, tobramycin and ciprofloxacin, and formulations of azteonam, amikacin, levofloxacin, ciprofloxacin and fosfomycin/tobramycin for nebulization. Clinical trials of anti-inflammatory agents, including glutathione, phosphodiesterase-5 inhibitors such as sildenafil, oral acetylcysteine, simvastatin, methotrexate, docosahexaenoic acid, hydroxychloroquine, pioglitazone and alpha1-antitrypsin, are ongoing. Ion channel modulating agents, such as lancovutide (Moli1901, duramycin) and denufosol, which activate alternate (non-CF transmembrane regulator [CFTR]) chloride channels, and GS 9411, a sodium channel antagonist, are now at the stages of clinical study and if successful, will offer a new category of therapeutic agent for the treatment of CF. Correction of the underlying gene effect, either by agents that help to correct the dysfunctional CFTR, such as ataluren, VX-770 and VX-809, or by gene transfer (gene therapy), is a particularly exciting prospect as a new therapy for CF and clinical studies are ongoing.

http://tinyurl.com/mal7ob

Continuous vs Thrice-Daily Ceftazidime for Elective Intravenous Antipseudomonal Therapy in Cystic Fibrosis. J. Riethmueller, S. Junge, T. W. Schroeter, K. Kuemmerer P. Franke, M. Ballmann, A. Claass, S. Broemme, R. Jeschke, A. Hebestreit, D. Staab, K. Koetz, G. Doering and M. Stern. Infection. Published online: 5 September 2009

Continuous or thrice-daily dosing of intravenous ceftazidime, both combined with once-daily tobramycin, are equally effective application regimens for elective

Continued on page 32

UNPLUGGED...
With Michelle Compton

By Richard De Nagel

Welcome to 2010. So what shall we call it? I am thinking twenty-ten, not two thousand ten. Twenty-ten is catchier, slick and hip. Not too dissimilar from the CF vs. cystic fibrosis or sixty-five roses vs. CF vs. cystic fibrosis choice. What is in a word anyway? Does it even matter? Do our words have any effect on us at all?

There is an idea about language that our choice of words can influence our thoughts, then dictate our actions. So with that philosophy our words influence the way we think. If I always think I am stuck in chaos and drama then my life is filled with crises and drama. Just a thought…

Our next person interviewed for Unplugged is the one, the only: Michelle Compton. She is an innovator, artist, visionary and overall groovy chic. Did you know that she started the Breathing Room? If you know the Breathing Room then you know what I mean about Michelle. The tag line for the Breathing Room is "the art of living with cystic fibrosis". I cannot imagine a better way to phrase having CF. It is an art to live with CF; it is not negative all the time, though it could be. It is not positive all the time, though it has its moments. When living with CF is described as an art, it gives it more complexity and texture. And that is a great choice of words to describe CF and Michelle.

So here she is:

1) Name – Michelle Compton

2) Age - 42 (had a bilateral lung transplant at age 31)

3) Where do you live?

In Mountain View, CA which is a smallish place in the greater San Francisco Bay Area - about a 45-minute drive to San Francisco.

4) When were you diagnosed with CF?

MICHELLE COMPTON HIKING IN AUSTRALIA.

I had undiagnosed health problems all my life. When I was 12, some doctor thought I had a wheat gluten allergy, so I was on a wheat-free diet for months. Yuck! This was in the early '80s, before the big health food chain stores, so wheat-free items were hard to find and yucky. But, I finally was diagnosed with CF at age 13- and no more wheat-free diet. This was huge for me because I loved KFC fried chicken, and even had two cousins who worked there. They would bring home freebies, and I couldn't eat it – I felt so left out! Of course, finding out I had this genetic illness really sucked. Even though my lungs were pretty good, they put me on a regimen of inhaled treatments and manual CPT and enzymes. So, I felt like when I went into the hospital I was fine, and that they 'gave me' this disease.

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

I belong to part of the Kaiser-Permanente system. It works pretty well for me. I really like my doctor, David Goya. I feel like we work together as a team to fix any issues I may have. In addition, the Kaiser CF centers in northern California have quarterly gatherings, so I feel like I get benefit from them coming together regularly to discuss tough cases.

6) How would you describe your health now?

Hmmm, I'm not sure how to answer that. My PFTs are good, and on paper my other numbers are good. But I had a stroke three years ago, and it has been a new struggle to recover. I started off with brain surgery. I was on a ventilator, had pneumonia, tube feedings, the whole kit and caboodle. I still have big issues with my balance. So I walk slowly, with a cane. I sound like I'm complaining. I don't mean to. There have been a lot of highs as well as some lows.

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

Newest music? I'm such a throwback! But I try to stay quasi-current, although I feel like I am always playing catch-up. Right now, I'm into Bitter:Sweet. You know, it's seasonal. They use it as the background music for some champagne commercial. And a couple of years ago, it was featured

heavily on "Grey's Anatomy". Sheepishly, that's where I first heard it.

8) What is your favorite music in your iPod/CD player?

Right now it's the holidays, and I am a sucker for Jazz-oriented Christmas music. So right now it's Michael Buble and Harry Connick, Jr.

9) Are you working? How are you doing with that?

Yeah, you could call it working. Most of my time is spent working for "Breathing Room", but it's all volunteer stuff - no salary. Some days, it's very hard to get stuff done. I have migraines that totally wear me out and, since my stroke, I physically wear out easier. But the other Board members have, or are close to, their own health stuff, so they understand. I'm usually pretty driven, and my own worst critic; so I hate when I miss a deadline due to my health BS.

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

I struggle with it. Most of my adult life, I have teeter-tottered between agnosticism and Buddhism - which is more a philosophy for me than a religion. I have to say that since my stroke, I have REALLY not felt any spirituality in me. I'm struggling a lot with that. I guess it's a certain type of grief - grieving another type of loss. Lately I find myself more and more bothered by my lack of spirituality, so I'm trying to do something about that. It feels weird to have to 'force' it and I wouldn't think it would be something that responded to force - either you believe or you don't, right? I don't know. Obviously, I don't have all the answers I need. Before my transplant, I got really spiritual, and it continued after the surgery, too. I questioned everything, including my purpose and why I was given a second chance. I'm sure that I'm not alone in questioning.

11) What are your hobbies? Does CF interfere?

My hobbies are mostly about art: photography, silk painting, soft pastel drawing, etc. CF never got in the way of that. They are solitary pursuits and you can go at your own pace. So treatments or coughing fits didn't come into play.

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

I've been in my current relationship for 10+ years. I could gush and gush about him. We met months after my transplant, so he didn't know all the hands-on CF stuff about me. But, that said, we had our hands full the first year post-transplant with all kinds of medical stuff, so he has passed his "trial by fire". He makes me want to be a better person. And he is strong, and very smart and multi-talented. What's not to love? When we first got together, we were very open about not knowing how much time we had together, and what hardships may be in store. I think the very honest communication, and willingness to leap into the unknown, really cemented our relationship. He's always accepted me, wholly. That means accepting that I'm a slob and a smart-ass, as well as all of my medical BS.

13) What is your most embarrassing CF moment?

My most embarrassing CF moment has to be more than one - but they are all similar. Clogging the toilet! Really severely!

14) What gets you through the tough days?

Knowing that there is a tomorrow, and it will be different. Some days, I just feel really down, and knowing that this state isn't permanent let's me just hide under the covers and wait for tomorrow.

15) What do you hate most about CF?

Hmm...that's a toughie. Maybe (because it's my current state, so, on my mind) it's the non-absorption and the stomach cramps. Sometimes I just can't power my way through and act all nice, and pretend nothing is wrong. So sometimes it's all I can do to just veg out on the couch and let the world pass by.

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

Okay, I watch waaayyyy too much TV, I know. So, it's hard to pick just one show. Right now my favorite is reruns of "The Office". I don't know why. It just makes me laugh and gives me a break from reality.

17) Do you have kids? Want them?

Nope. No kids. That's one thing Stephen and I talked about early on in our relationship; we love being aunts and uncles, but each of us has no desire to be a parent.

18) What do you have hope for?

I try not to have hope for any particular thing. I know that sounds pessimistic, or even fatalistic. But I try to be openly "hope-full" without attaching it to a certain outcome. It's hard to sit down and explain. With my CF, I hope that whatever is supposed to happen does. If I am supposed to get sick, then I do, and I fight to combat it. If I am supposed to get a certain job, then I will. I still try like hell (can I say that?) to not get sick, or to do my best in a job interview.

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

Honestly, I think it's neutral. Life is a series of 'good" and "bad" – and I see my CF as balancing out. Sure, there were treatments, and IVs, yada-yada. But it had a hand in shaping who I am as an adult - helped shape my core values, my belief system, and I don't think those are "bad".

20) Tell us about your friends?

My friends: Well, now. I guess I would say that the majority of my friends are in the CF community.

Continued on page 32

DENAGEL *continued from page 31*

They tend to be compassionate, and supportive, and I like that about them as a whole. I guess I don't have many casual friends. Either I am serious about our friendship – which comes with compassion and support – or I don't have time for it.

21) What is your favorite color?

Oh, my favorite color changes from time to time. Right now, it probably is purple. But it's been teal, aqua, leaf-green. I guess I favor "cool" colors.

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

My CF friends are VERY important to me. They truly get what I'm going through. And, the circle of friends I belong to all share a world view. More and more, I rely on the internet and the phone to maintain my CF friendships - that's often a matter of schedules, as well as cross-infection stuff.

23) Do you spend time educating yourself about CF? How important is this to you? What effect does this have on your treatments? Rapport with your doctors? Self-image?

I am falling down on the CF-specific treatments. Being this far out post-transplant and not having a lot of CF symptoms, they are simply not often applicable. But I do try to "keep my ear to the ground" and attend some lay conferences, and read some online to keep up with stuff. Also, it seems so much more complicated now than it was in the '80s and '90s - many more options. It's exciting - and overwhelming! I do feel like I have a better rapport with my doctors. Even if I don't know the specifics of a certain drug, we can discuss the pros and cons of it and I think that, overall, that helps both of us. I don't feel like I've been 'steamrollered' and he has gotten a patient's participation in decision-making. I think it benefits us both. As for self-image, I never really thought of it. But, yeah, I guess having some knowledge makes me feel more powerful which, in turn, bolsters my self-image.

If you do not know about it, the "Breathing Room" is art exhibition of a photo with a poem or written word by the person who is in the picture. It is an amazing array of different photos from the good, the bad and the ugly of CF. It does a great job of capturing CF. (As a quid pro quo, Michelle has now trapped me into doing an image, so keep your eyes out for my photo.) And if you have not seen it, you can see it here in CF Roundtable. We publish a page each issue; it is one of the color pages with a photo and a poem. Or you can see it on their website: www.thebreathingroom.org.

Michelle is so honest and courageous. She has worked hard to stay alive and is doing great. She embraces what comes and fights hard. Tough days and feelings are something to deal with, not to pretend they don't exist. But deal with them and move on, as she does. There always is another day. It is not all good or bad, or happy or sad. And remember to choose your words wisely. And if you can't remember your choice of words, try to be aware of the words you choose. They will teach you a lot, as Michelle teaches me a lot. Check out the "Breathing Room"! ▲

Rich is 41 and has CF. He is a Director of USACFA. His contact information is on page 2.

TILLMAN *continued from page 29*

antipseudomonal therapy in clinically stable patients with CF.
http://tinyurl.com/ybkjtww

Inhaled Mannitol Improves the Hydration and Surface properties of Sputum in patients with Cystic Fibrosis. Evangelia Daviskas, MBiomedE PhD, Sandra D Anderson, PhD DSc, Anna Jaques, BSc MPH and Brett Charlton, MBBS PhD. Chest. Published online before print October 31, 2009

Treatment with inhaled mannitol over 2 weeks improved the hydration and surface properties of sputum in patients with CF. This effect was sustained and correlated with airway function changes.
http://tinyurl.com/yz2kz6j

Aminoglycoside therapy against Pseudomonas aeruginosa in cystic fibrosis: A review. Felix Ratjen, Florian Brockhaus, Gerhild Angyalosi. Volume 8, Issue 6, Pages 361-369 (December 2009)

In patients with cystic fibrosis (CF), respiratory infections with the opportunistic bacterial pathogen Pseudomonas aeruginosa (Pa) have a major impact on morbidity and mortality. Aminoglycosides, especially tobramycin, have been used successfully to combat these infections. Aminoglycoside penetration of bronchial secretions is poor when the antibiotic is administered intravenously. Nebulization allows direct delivery of the drug to the sites of infection within the airways, while avoiding systemic exposure. Published clinical data show that inhaled tobramycin reduces the bacterial load, improves lung function and reduces the number of hospital admissions. Inhaled tobramycin has been used successfully to eradicate Pa in patients with early infection. Maintaining clinical benefits requires chronic tobramycin treatment, and the concept of chronic intermittent inhaled treatment (typically, alternating drug and drug-free periods of 28days) was introduced to minimize

the emergence of aminoglycoside resistant Pa strains. Other therapeutic advances include the development of different tobramycin formulations and nebulizers that reduce delivery time without compromising efficacy. An optimal treatment regimen for patients with CF with early or intermittent Pa infections remains a high priority to maintain long-term lung health.
http://tinyurl.com/ylbv5vo

LUNG TRANSPLANTATION

Prior diabetes mellitus is associated with increased morbidity in cystic fibrosis patients undergoing bilateral lung transplantation: A retrospective case-control study. Bradbury, R. A.; Shirkhedkar, D.; Glanville, A. R.; Campbell, L. V. Internal Medicine Journal, Volume 39, Number 6, June 2009, pp. 384-388(5)

The aim of this study was to determine whether pre-existing diabetes mellitus increases the risk of rejection, infection and/or death in CF patients undergoing bilateral sequential single-lung transplantation. Almost all CF patients develop hyperglycemia after lung transplantation, but patients with prior diabetes have more complication-related admissions to hospital and a higher mortality rate.
http://tinyurl.com/mkf7pg

Predicting survival in end-stage cystic fibrosis. Robert I. Ketchell, Michael Roughton, Penny Agent, Khin Gyi, Margaret E. Hodson. Respiratory Medicine. Volume 103, Issue 10, Pages 1441-1447 (October 2009)

The natural history of cystic fibrosis (CF) is unpredictable and the optimal timing for lung transplantation in end-stage disease uncertain. Predicting survival based on FEV1 alone remains controversial and therefore the aim of this study was to assess the value of walk test performance in pre-transplant assessment. Resting heart rate was the only consistent parameter in this study at predicting a high risk of dying on the transplant waiting list.
http://tinyurl.com/pdylrw

LIVER DISEASE

Hepatobiliary Abnormalities and Disease in Cystic Fibrosis: Epidemiology and Outcomes Through Adulthood. Bhardwaj, Sidharth MD; Canlas, Karen MD; Kahi, Charles MD; Temkit, M'Hamed MS; Molleston, Jean MD; Ober, Michael MD; Howenstine, Michelle MD; Kwo, Paul Y. MD. Journal of Clinical Gastroenterology: October 2009 - Volume 43 - Issue 9 - pp 858-864

Abnormal liver chemistries in CF are common though most of CF patients lack clinical evidence of liver disease and the severe complications of fibrosis/cirrhosis are rare. The risk of liver involvement decreases significantly with age, falling by 10% per annum for those described as having CF-related hepatobiliary disease. CF-related hepatobiliary disease is a rare occurrence after age 18.
http://tinyurl.com/ybfym3b

Genetic Risk Factor for Liver Disease for Patients With Cystic Fibrosis. Leslie H. Lang. Gastroenterology. Volume 137, Issue 5, Page 1546 (November 2009).

A genetic analysis indicates that a certain gene variation in patients with CF may significantly increase their risk of developing severe liver disease.
http://tinyurl.com/yl7s2sd

CFRD

Cystic fibrosis related diabetes. Jacquelyn Zirbes, Carlos E. Milla. Paediatric Respiratory Reviews. Volume 10, Issue 3, Pages 118-123 (September 2009)

Diabetes is a frequent complication seen in CF patients as they reach adulthood. Cystic fibrosis related diabetes (CFRD) is distinguished as a separate entity with features that include progressive loss of islet beta cell mass and insulin deficiency, as well as insulin resistance. Abnormalities in glucose tolerance may be detectable for many years prior to the development of overt diabetes. Therefore oral glucose tolerance testing is the preferred screening method for the identification of those patients at the highest risk for progression to diabetes. Progression to diabetes has been linked to poor outcomes in CF including loss of pulmonary function and increased

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Mailbox

I do enjoy *CF Roundtable*. When it comes, I can't put it down till I look at the whole newsletter. There always are very interesting articles. I enclose a check in memory of our son, Ken, who would have been 47 on November 24, 2009.

Thank you,
Carol O'Brien
Frankfort, IL

Your efforts to educate and support the CF community are so valuable and appreciated.

Judith Riley
Brooklyn, CT

I have always found your newsletter to be very informative as well as providing insights for all individuals with CF.

Johanna Libbert
Richland, IN

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mortality among females. Given the role that insulin deficiency plays in CFRD, insulin replacement therapy remains the only recommended intervention. In the absence of definitive supportive data, the use of oral antidiabetic agents is not considered standard therapy and needs further study. As with other forms of diabetes, CFRD patients also experience microvascular complications and should be periodically evaluated for manifestations.
http://tinyurl.com/nlp4py

Natural History of Glucose Intolerance in Patients with Cystic Fibrosis: Ten-Year Prospective Observation Program. Anca E. Sterescu, MD, Bronwen Rhodes, MB ChB, Reuben Jackson, MB BS, Annie Dupuis, PhD, Amir Hanna, MD, David C. Wilson, MB ChB, Elizabeth Tullis, MD, Paul B. Pencharz, MB ChB, PhD. The Journal of Pediatrics. Published online 04 December 2009.

Annual screening of glucose tolerance in patients with CF reveals highly variable results over time. Fluctuating levels of insulin resistance, probably with variable degrees of ongoing inflammation, affect the results and hinder prediction of future development of CFRD. Home glucose monitoring following abnormal OGTT results was essential in establishing the diagnosis of CFRD.
http://tinyurl.com/yz8l5zr

Cystic Fibrosis Related Diabetes: Current Trends in Prevalence, Incidence and Mortality. Antoinette Moran, Jordan Dunitz, MD, Brandon Nathan, MD, Asad Saeed, MD, Bonnie Holme and William Thomas, Phd. American Diabetes Association. Published online before print June 19, 2009.

CFRD diagnosis and management have changed considerably since diabetes was first shown to be associated with a poor prognosis in CF. Current trends in CFRD prevalence, incidence and mortality were determined from a comprehensive clinical database. Previously noted gender differences in mortality have disappeared, and the gap in mortality between CF patients with and without diabetes has narrowed considerably. It is believed that early diagnosis and aggressive treatment have played a major role in improving survival in these patients.
http://tinyurl.com/n8u4jq

FYI

Focus on Magnetic Resonance Imaging. Hans-Ulrich Kauczor, Julia Ley-Zaporozhan and Sebastian Ley.

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

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The Proceedings of the American Thoracic Society 6:458-463 (2009)

Magnetic resonance imaging (MRI) of the lung has shown tremendous progress in recent years. This includes parallel imaging, new contrast agents and mechanisms, ultrafast imaging, and respiratory gating. With these improvements in speed and image quality, MRI is now ready for routine clinical use. The main advantage for MRI of the lung is its unique combination of structural and functional assessment within a single imaging examination. This comprehensive imaging assessment is an asset when compared with computed tomography, which is complemented by the fact that MRI does not carry any exposure to ionizing radiation, making it especially advantageous in children, young adults, and for follow-up examinations either in disease surveillance or therapy monitoring.

http://pats.atsjournals.org/cgi/content/abstract/6/5/458 ▲

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

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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/
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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

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