CF Roundtable
A NEWSLETTER FOR ADULTS WHO HAVE CYSTIC FIBROSIS
AUTUMN 2013

Go Vegan And Nobody Gets Hurt

By Tom Martin

A little about myself: I grew up in Santa Cruz, CA, and currently live in Aptos. I'm an avid mountain biker, and I work from home as a full time Mechanical Designer Drafter. I love my CF friends and CFRI retreat.

I've learned a very good lesson over this summer: in a nut shell, eating a strictly vegan diet (plant based) is the best decision I've ever made. My girlfriend, Theresa, has been vegan for many years now; since we've been together for the last three years, I've been uncertain and skeptical about that way of eating, especially for a CF person.

So the story started when Theresa and I went on a great trip to Costa Rica in June 2013. This was a fun and adventurous trip, and I saw so many beautiful sights. But the real score here was the education I received from Dr. John McDougall, who is an MD and has written many books about how eating a plant based diet could eliminate so many of the diseases that are common in the U.S. One notable book is "The Starch Solution". I, of course, was skeptical, but I was willing to listen to the facts and research that he had been working on for the last three decades. Dr. McDougall's presentations were very impressive and scientific. There is too much to talk about here, of course.

TOM MARTIN ON HIS MOUNTAIN BIKE.

The gift of knowledge can be very powerful sometimes, and this is definitely one of those times. So, I decided to take a 30-day challenge and eat only vegan, no dairy and no meat of any kind. I have to say at the time I was a bit scared and worried that I might lose too much weight because I have CF. My other worries included would I get enough protein in my diet, would I lack calcium from milk and, of course, would I lack the taste and enjoyment of eating my favorite foods? The important lesson I learned in Costa Rica was that those myths were completely

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INSIDE THIS ISSUE

CF ROUNDTABLE
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EDITOR'S NOTES

I can't believe that summer is gone and autumn is here - with a vengeance. Our long, hot, dry summer turned into the wettest September on record. Oh, well, such is life. That's what keeps Oregon green.

We were sorry to learn of the death of past USACFA director **Patrick Hannegan**. We will miss you, Pat.

This issue has some interesting thoughts on the new cross- infection control policy of the CFF. There are, as always, more than two sides to this topic. After reading the articles by **Julie Desch** – (One Is The Loneliest Number) page 10, **Lisa Zaccharia** – (Voices From The Roundtable) page 18, and **Steve Shepherd**, **Paul Quinton** and **Eric Goodrich** – ("You're Not Welcome" – The CF Foundation's New Ban) page 21, you will have a better understanding of how this affects each of us. **Laura Tillman** continues the theme with a discussion about a presentation that was made at the 2013 CFRI conference. See "Vindication and Validation!" on page 6.

We hope that these articles will help you to be better informed and to be better able to make your own decisions on when or whether, you will be around others who have CF. And, if you are around others who have CF, how you will behave.

Jim Chlebda talks about some dramatic storms that occurred and the beautiful blooms that came after them. In the "Conversation Corner", **Tom Martin** writes of his experience with a vegan diet.

Our Focus topic is: "Living With Pain". **Andrea Eisenman**, writes of a new cause of pain for her – an injured knee - and how she is coping with it. **Kathy Russell** continues the topic in "Speeding Past 50", where she writes of different ways to control pain.

Once again, Laura Tillman has done a terrific job of gathering, sifting and reporting on "Information From The Internet".

Check out "Looking Ahead" on page 2. Perhaps there is an upcoming Focus topic on which you would like to write. We would love to receive an article from you. You can contact us for more information.

With the holidays coming, this is a good time to make a donation to USACFA in honor of or in memory of a friend or loved one. Donations make very nice gifts and they don't have to be wrapped.

Be sure to remember that it is time for flu shots. There are different types and different strengths, so you need to discuss it with your doctor.

Until next time, stay well and happy,
Kathy

Publication of CF Roundtable is made possible by donations from our readers and grants from Sustaining Partners - AbbVie, Boomer Esiason Foundation, CF Services, Foundation Care, Genentech, Gilead Sciences, Hill-Rom, and Vertex.

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

Wedding

Andrea Eisenman & Steve Downey
New York, NY
5 years on Sept 13, 2013

Beth Sufian & James Passamano
Houston, TX
25 years on July 2, 2013

NEW BEGINNING

Birth

Erica Lynn & Carl Fleming, Jr.
LaVista, NE
A daughter, **Layna Catherine Fleming**
Born on July 18, 2013

KEEPING YOUR INFORMATION CURRENT

To keep our records up to date, please be sure to complete and return a subscription form, on page 27, to us or register online with any changes to your information, www.cfroundtable.com. (Any issue of the newsletter that is returned to us costs us about two-and-a-half times the first-class postage rate for that piece. Currently that runs about $3.73 per returned copy.) **Thank you for helping us with this.**

LOOKING AHEAD

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

Autumn (Current) 2013: Living With Pain.

Winter (February) 2014: Memory Problems. (Submissions due December 15, 2013.) Have you noticed problems with your memory? Are there times that your memory isn't as good as usual? Have you discovered the causes for such memory problems? How do you deal with it?

Spring (May) 2014: Maintaining Mental Health. (Submissions due March 15, 2014.) Do you have any tips for maintaining an even keel on the rough seas of life? Have you found something that really works for you? Do you use medications, counseling, or something else to keep your mental balance? Please tell us how you manage.

Summer (August) 2014: Dealing With Conditions That Are Part Of CF. (Submissions due June 15, 2014.)

SPEEDING PAST 50...

Having Pain Can Be A Real Pain

By Kathy Russell

Pain is something that I wish on no one. I am delighted when I learn of someone who has no pain. Would that we all could say that we have no pain. Many of us have pain that is with us every day. I have written about my back pain and arthritis pain in prior issues of this newsletter. I'll not bore you with those same stories. Instead I'll tell you how I have handled other pain.

The worst pain I ever experienced was with my chronic sinus infections. My poor old sinuses took a beating from infections. At times, my head felt as if it were a five-cup-size balloon with five gallons of stuff in it. There was such pressure behind my eyes that I could barely tip my head forward. The pain was constant and the only change in it was when it got worse.

If I stepped from a warm place into the cool outdoors, it was as if someone had hit me in the face with a sledge hammer. My sinuses could not stand any changes in temperature or pressure. When the infamous "East Wind" of the Columbia River Gorge was blowing, I had to stay inside. I just couldn't stand the pain.

The only pain medicine that had made any difference in the pain level was a narcotic that inhibited my breathing. Since I am a lazy breather, (I sometimes forget to breathe) it didn't make sense to take that very often. It was just plain wasteful to take over-the-counter types of pain meds; they didn't even touch that pain.

It got so bad that I had to sleep sitting up because I couldn't breathe lying down. I finally had to admit that I needed surgery. I had been putting it off for several years and I couldn't bear it anymore.

When I had that first sinus surgery, the relief of getting the "gunk" out of my sinuses was so profound that I didn't need any post-op pain medication. The nurses couldn't believe that I didn't need pain meds. Holes had been cut through my mouth into my skull and, still, it didn't hurt compared to how it felt before surgery. I explained that what I was feeling was far less painful than my sinuses had been for many years. I had a wonderful feeling of relief.

The next most painful time that I had was after abdominal surgery. I was split from sternum to pubis, right down my middle. Everything inside had been thoroughly prodded and handled. Even though I had an epidural catheter (a tube in my spinal column to instill painkiller into my spine) I still experienced one bout of awful pain. My pain level had been staying at about a three or four, on a scale of one-to-ten, and suddenly it jumped up. When the nurse asked me what my pain level was – on a scale of one-to-ten – I said it was a 27!! That time I accepted a shot of morphine to get me over the hump. Once that episode was over, I was okay again.

> *"I used my favorite alternative method of pain control. I called my sweet husband, Paul, and asked him to make me laugh."*

KATHY RUSSELL

One evening, a few days later, I was experiencing an increasing amount of pain. I wanted to call for a nurse, but they all were busy with a "code blue" in the room next to mine. So I used my favorite alternative method of pain control. I called my sweet husband, Paul, and asked him to make me laugh. (I have found over the years that a merry heart really does "doeth good like a medicine".) He proceeded to relate a story about our dogs and some of their antics. As I remembered that happening, my pain lessened and I was fine. Sometimes just getting one's mind off of the pain can make it better.

Another method of pain control that I use is staying busy enough that I can't think about it. I may get involved in a project that takes concentration. If I get lost in that, then I

can't think about my pain. It works – sometimes.

An example of that type of pain control is what I did this week. On Wednesday, Paul and I went to the home of friends. The man is a Master Gardener. This year he turned 80 and in honor of that venerable age, he planted 80 tomato plants. Last spring he told me that he would have all the tomatoes I would need for my canning. Last week he had asked me when I would like my tomatoes and I said this week would be fine. Paul and I picked about 75 pounds of tomatoes on Wednesday. On Thursday, we canned 21 quarts of lovely tomatoes. On Friday we canned another 14 quarts. It took a lot of work, but the results are terrific. Even though my back was really tired and sore, I didn't notice it as much while I was working. (When I sat down, I really noticed!)

Our summer was fantastic! We had such wonderful weather. We had only a few days that were really too hot. The last half of June, all of July and August, and the beginning of September were filled with days mostly in the mid-70s to high-80s, low humidity, only a trace of rain and fairly cool nights. Who could ask for more? I loved it and I felt great, other than being tired. When I asked my doctor about why I was so tired, he was stumped. More on that later…

Right now, I am wrestling with a different type of pain. It is emotional pain. First is a sense of loss. Several friends have died and I really miss them. I know that everyone will die eventually; I just don't happen to like it when my friends die. They always are younger than I am and they have so much to live for. Ah, but life isn't fair.

A second type of emotional pain is the loss of certain abilities. Over the past few years, I have lost a lot of my sense of touch, most of my senses of smell and taste, my eyesight is not as sharp as it once was, neither is my hearing and my endurance is almost not there at all. I can remember when I could work rings around my current self without ever breaking a sweat. Now, just walking across a room is tiring.

> *"It's funny to remember that when I was much younger I felt that since I already had one disease (CF) I shouldn't have to worry about getting any other disease, such as cancer."*

Did I say I was tired? That brings me to a third kind of pain – getting unpleasant surprises! Perhaps part of my sense of being tired is that I have been diagnosed with breast cancer and will have bilateral mastectomies to remove that cancer. It's funny to remember that when I was much younger I felt that since I already had one disease (CF) I shouldn't have to worry about getting any other disease, such as cancer. Of course, life doesn't work that way. No one ever said that life was fair or that having one disease could protect you from another, but we always hope that it will.

I am not at all concerned about the surgery. I have great docs and they have given me good counsel. I was able to make my choices with no pressure from them. Since I don't want to have more than one bout of anesthesia, having the surgical portion of my recovery done all at one time seemed to be the wisest choice. I will have no reconstruction done. Don't worry, I hadn't made any plans to become a nudist or to go topless, so I'll do fine.

I will make this suggestion to all the women out there – please be sure to talk with your doctors about mammograms and be sure to get them as suggested. Finding cancer early is important. Mine is a very early cancer and should be very treatable.

I know that many people are scared of getting a diagnosis of cancer. I always had wondered how I would respond to such a diagnosis. Well, I found out. When the doc told me I have invasive ductal carcinoma, my thought was – hmm, something else to have to bother with. When I hung up the phone, I said, "Well, crap!" That has been the extent of my anger.

At the end of my meeting with the cancer surgeon, she was surprised that I didn't have a lot of questions and didn't seem to be particularly upset. I told her that it wasn't "that I don't care about having cancer: it's just that this is only another bump in what has been a long and bumpy road of life." After my surgery, I will be a survivor.

So, life goes on and we make the best of it. Pain is a real pain in the backside, but we can handle it. I hope you all have a pleasant autumn and that winter will be kind to all.

Be sure to check with your docs about getting flu shots. It's that time, again. Stay healthy and happy. ▲

Kathy is 69 and has CF. She lives with her husband, Paul, in Gresham, OR. Her contact information is on page 2.

Vindication and Validation!

By Laura Tillman

Another year and another CFRI conference. This year's conference proved to be particularly good. I enjoyed the speakers, the attendees, the exhibits, the food, and the company of everyone involved with the weekend's activities. I always feel such warmth, friendship and camaraderie; it seems odd that there are so many people that I feel such a closeness to, although we only get together at CFRI. I guess that's why we're referred to as the CF community!

So, you ask, why would I title my article regarding the weekend "Vindication and Validation"? Well, for those of you who know me, you've come to the realization that I'm rather germaphobic. And, one of the speakers turned out to be a kindred spirit!!! Katherine Y. Yang, Pharm.D., M.P.H., Department of Clinical Pharmacy, University of California, San Francisco, gave a talk entitled, "Should We Live in a Bubble? Best Practices in CF Infection Control". It was so fantastic to hear someone sharing my viewpoints - and it proved to my husband that I'm not entirely overboard with the measures that I practice. Hence, vindication and validation!

Dr. Yang started by stating that we should follow standard precautions which apply to all patients (as well as everyone else) in all situations. First and foremost is proper hand hygiene, followed by disinfecting surfaces and equipment, cough etiquette, and appropriate use of Personal Protective Equipment (PPE) which includes gloves, masks, gowns, goggles and face shields, if needed, in order to reduce exposure to germs.

> "Dr. Yang underscores the fact that it is ABSOLUTELY fine to ask any personnel (including healthcare providers) who walk into your room to wash their hands or use alcohol gel."

She then went on to discuss other types of situations where precautions are needed:

1. Contact, or touch, which is the most common way to spread germs. Direct contact occurs by sharing respiratory secretions, as in kissing. Indirect contact transmission occurs by touching a patient's environment, or by using contaminated equipment.
2. Nebulizers (in hospitals or if shared at home between siblings)
3. Toys (including computers and electronic games)
4. Shaking hands
5. Droplet transmission which occurs when droplets that are formed as a person sneezes, coughs, sings, spits, or has some type of respiratory procedure done, come in contact with another person's nose, eyes or mouth. FYI - droplets travel 3-6 feet! Airborne droplets can be carried on air currents, dust particles and suspended in air for longer periods of time and longer distances and occurs via inhalation. So, get those toothbrushes off the counter in your bathroom!!!!

LAURA TILLMAN

Dr. Yang then spoke about the major germs in CF, how they are spread, their effects on the CF lung and, most importantly (to me), where they are found. Pseudomonas is found in the natural environment, sinks, faucets, drains, swimming pools, hot tubs, whirlpools and, of course, in hospitals and clinics. And if that isn't enough, it's in your salad!! In other words, Pseudomonas is everywhere and there is no way to avoid it. B. cepacia is also

found in the natural environment (watch out for those plants and rotting onions!), as well as contaminated medical devices, medications and antiseptic wipes.

Feeling safe? No? Well then, you and everyone else need to follow some general infection control guidelines as well as those specific to CF. Besides the ones mentioned earlier in this article, Dr. Yang suggests that you stay away from sick contacts; cover your cuts and scrapes; avoid contact with other's cuts and scrapes; avoid touching your eyes, nose, mouth; avoid sharing personal items; get immunizations. Additionally, she recommends that you always know your respiratory cultures, avoid face-to-face socializing with others with CF, and maintain a distance of 6 feet (as opposed to the old guideline of 3 feet). These same guidelines apply, regardless of lung transplantation.

Dr. Yang did emphasize that one must use common sense regarding infection control. For example, while you should maintain a clean, dust-free environment, there's no need to go crazy; there's only so much that one can do and control. Pets are fine to have, just don't have the CF patient change the kitty litter! While chlorinated swimming pools are okay to go in, one should avoid hot tubs. And avoid digging in dirt - which, sadly, means no gardening for those of us who love plants.

There were also some pertinent points for the clinic or hospital besides following the 6 foot rule and bringing your own electronic equipment to use/play around with. Dr. Yang suggests wearing a mask regardless of your cultures. She also emphasizes that ***EVERYONE*** "Gels in and gels out" even if they don't touch anything. And, she underscores the fact that it is ABSOLUTELY fine to ask any personnel (including healthcare providers) who walk into your room to wash their hands or use alcohol gel.

And speaking of hand gels - not all hand gels are created equal. You should only use alcohol-based sanitizers that contain at least 60% alcohol. Interestingly, Dr. Yang considers these to be better than soap and water - unless your hands are obviously dirty. Additionally, she feels that antibacterial soaps increase the risk for antibiotic resistance in Pseudomonas and does not think they are necessary. She then demonstrated proper hand gel technique, which appeared to be very similar to hand washing technique. As for "natural sanitizers" such as tea tree oil, there's not much data available.

Now, if you think you have a good basis for where germs lurk and what to do about them - this is just the tip of the iceberg! Germs are everywhere and we can't avoid them. We can take precautions and do our best to avoid unnecessary exposure to them.

So, why in the world do I attend a conference where others with CF will be? Well, although I'm a germaphobic, I would never choose to live in a bubble. I travel and go places where there are crowds. I attend conferences (CFRI) with other CF adults and I socialize with others who have CF. We know what to do and abide by infection control guidelines and use common sense. There are some friends that I'll meet out-of-doors due to what they culture. There are others that I'll - GASP - hug. We know our cultures and we know how much our friendship means. I never know if this will be the last time I'll see someone, and we're not going to let fear run (and ruin) our lives.

So, I do take chances; but life is a chance. And to be perfectly honest, I fear those without CF more than I do those who have CF. CF adults know about infection control guidelines - those without CF usually have no idea or don't care. So, I practice being a germaphobic, but I also live life to the fullest - germs be damned! ▲

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

Call to All Artists

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

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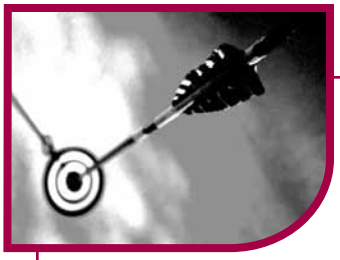
Please include your name and contact information.



FOCUS TOPIC

LIVING WITH PAIN

Working Through The Pain

By Andrea Eisenman

Lately, I have had a few painful injuries: mainly, it has been my right knee. And usually, it has been while I was playing tennis. I am an addict to the game. Not really sure why, but maybe it is because when I am playing, I am consumed by it mentally and physically and am not thinking of anything else. Is it my escape hatch? Or do I love it because during the years CF had taken its toll on my lung function, I was unable to play for almost 30 years? Maybe it is a little of both. It is also an all-around physical activity that helps me keep my lungs clear.

When I get injured, I am upset because I am feeling intense pain, but also because I may not be able to play tennis for an uncertain amount of time.

The first time I injured my knee was last February. I could barely walk and when I did, I heard a clicking sound that really upset me. Like, what did I do now?! It turned out that I was diagnosed with something called AVN (Avascular Necrosis). I had a chip in the upper knee joint. It is a common occurrence when one is taking prednisone for a period of time. It is the dying of bone tissue from the drug cutting off the blood supply to that area. I have been on prednisone for thirteen years since my lung transplant and will be on it for my lifetime. I am reminded of the saying, about transplant: "It is the trade-off of one disease you know for the many you don't."

During my shock at this new diagnosis, I was told that I would possibly need a partial knee replacement followed by many months of being on crutches and a lot of physical therapy. I was told to take Advil or Aleve for the pain. Since I am a transplant recipient, taking the NSAIDs mentioned above was not possible. My kidney function is at risk due to the immuno-suppressants, so I could only take Tylenol or an opiate. Knowing what I know about Vicodan and Oxycontin - how easy it is to build up a tolerance and become addicted - I decided to use Tylenol, which barely does anything to stem the pain. I also rested for a week and stayed off my knee, which is a rarity for me. Icing it also helped when it flared with pain. The pain was intense but, eventually, it eased up and I could see an improvement.

> "I found it hard to adhere to an extra 35 minutes of exercise to add to my daily health regimen, but the benefits outweighed the downside."

ANDREA EISENMAN

Thankfully, the orthopedist I went to understood my need to keep moving for my lung's sake and diabetes. The doctor said that I could start biking a week after my injury. He instructed me that after my knee healed from the fracture from AVN, which could take about six weeks, I could start a physical therapy regimen. And, if that didn't help, I would need surgery that would put me out of the game for almost a year.

I was dubious about the efficacy the physical therapy (PT) would bring me. Luckily, I was happy to be proven wrong. After about eight weeks of PT and biking, I was playing tennis again. I was so relieved that my pain was much less intense. The only caveat was I would need to continue PT, on my own, every other day, for the rest of my foreseeable future if I wanted to keep my knee healthy. Because I didn't want the pain coming back, I was compliant.

I found it hard to adhere to an extra 35 minutes of exercise to add to my daily health regimen, but the benefits outweighed the downside. These PT exercises also helped my back pain that had been reoccurring with playing tennis too often or two days in a row. I was so thrilled. Then I injured

myself again, just two weeks ago; same knee but different pain. At the time I was playing tennis and was not sure if it was an exacerbation of AVN or something new. It felt like it was different as I could not bend nor totally straighten my knee without seeing stars from pain.

After seeing another orthopedist (my previous one has left New York) it was suggested that it might be a bigger tear in my meniscus. My two previous MRIs showed small tears around the knee with AVN. The good news is that the AVN did not progress. The bad news is that I may need surgery to correct the tear. I will start PT this Friday and I am hopeful that I can work through this, as I did the time before.

Currently, my pain level is decreasing but there are times when it is quite disruptive and keeps me from doing anything but icing it and sitting still. I do have an added pain reducer in my arsenal called Voltaren. It is a topical anti-inflammatory gel that is not absorbed too much through skin. It works enough to help me walk around and work through my pain to keep moving.

As pain goes, it has been challenging but not insurmountable. I have been through worse, having had a spinal fusion at 16 and a bilateral lung transplant at 35. I found what helps is having hope that I can overcome this pain and move on to better times and lots of tennis. ▲

Andrea is 48 and has CF. She is a Director of USACFA and is the Executive Editor of CF Roundtable and Webmaster. Her contact information is on page 2.

Information from the Internet...

Compiled by Laura Tillman

PRESS RELEASES

Pulsating Aerosol Offers a New Approach in the Respiratory Therapy of Cystic Fibrosis

Around 65% of CF patients have intermittent or chronic rhinosinusitis (CRS). In CF patients, the upper airways act like a reservoir for bacteria, which can then spread from there into the lungs. The genotypes of microorganisms in the upper and lower airways are invariably identical. The aim is to use conservative means to prevent the development of CRS and avoid the need for sinonasal surgery. The PARI SINUS inhalation device is particularly suited as a conservative therapy. It produces a pulsating aerosol and, by creating differences in pressure, promotes ventilation of the paranasal sinuses. In contrast to nasal sprays, the pulsating aerosol actually reaches the paranasal sinuses and demonstrates a longer retention time. Pilot studies have confirmed the efficacy of the PARI SINUS in improving the quality of life of CF patients.

http://tinyurl.com/qdnwvha

AmpliPhi Releases Data on Phage Therapy for Treatment of Lung Infections in Cystic Fibrosis Patients

AmpliPhi BioSciences Corp. presented data relating to the use of bacteriophages in the treatment of Pseudomonas aeruginosa (P. aeruginosa). Bacteriophages are able to penetrate biofilms and replicate locally to high levels, to produce strong local therapeutic effects. Biofilm degradation by bacteriophages kills bacteria and could also potentially restore the efficacy of antibiotics. Studies show that bacteriophages can infect both mucoid and non-mucoid P. aeruginosa strains isolated from CF lungs, whether or not they were antibiotic resistant; they were as effective as a known high dose of antibiotic but also appeared to be more effective and faster at preventing the dissemination of the bacteria to the lung and oropharynx. The use of bacteriophage helps eliminate the infection earlier, which in consequence results in a lower inflammatory response.

http://tinyurl.com/q9oddv4

Target 2 Forms of Iron to Control Cystic Fibrosis Lung Infection

The bacterium Pseudomonas aeruginosa needs iron to establish and maintain a biofilm in the lungs of cystic fibrosis patients, and therapies have been proposed to deprive the bacteria of this necessary element. However, these techniques may not work because they only target one of the two types of iron that are available in the lung. Current therapies focus on removing ferric iron [Fe(III)] but leave plenty of ferrous iron [Fe(II)] behind for the bacteria to use. The concentration of Fe(II) present in the lungs of patients with cystic fibrosis correlates with disease severity, a sign that pathogens not only use ferrous iron - they thrive on it. An optimal concentration of bioavailable iron is needed to establish

Continued on page 11

One Is The Loneliest Number

By Julie Desch

I am not by nature quick to anger. I get along well with others and share my toys. Always have. But when the Cystic Fibrosis Foundation recently pronounced that they were going to make future risk/benefit decisions for me, I became quite angry. In this case, however, anger is a good emotion because it has motivated me to become a rebel. As such, my regularly scheduled programming will be interrupted to bring you this important public service announcement:

The CF Foundation has appointed a committee of 21 people to revise and update its 2003 *Infection Control Recommendations for Patients with Cystic Fibrosis*. The group includes physicians, researchers, nurses, parents, a respiratory therapist, a social worker, and **exactly one adult with cystic fibrosis** (who also happens to work for the Foundation). At the time of this writing, a 98-item publication is circulating for review in draft form, with the final policy to be discussed at the 2013 North American Cystic Fibrosis Conference this October. I have attended several of these conferences in the past. They are informative, interesting, and a great way to stay up to date with all that is happening in the CF world. Sometimes, I even see a friend or two with CF in the audience. But I won't be going this year, or ever again, apparently. I'm guessing that I won't be the "invited guest" any time soon after this has been aired.

Many of the 92 items are absolutely sound, appropriate, and based on proven science. Yet, there are a few that leave me scratching my head, and one that leaves me speechless with dismay. Specifically, item seventy-two of the list of the Foundation's Decree states:

The CFF recommends that only one person with CF attend CF Foundation-sponsored, healthcare-sponsored or CF Center-sponsored ***indoor events*** *(e.g., CF Education Days) to reduce the risk of person-to-person transmission.*

Though this states that the Foundation only "recommends" that one person attend, a quick glance of their website reveals much more forceful language:

At any Foundation-sponsored indoor event or meeting, including gatherings such as chapter committee meetings, only one person with CF may be present and he or she will be designated in close consultation with event chairs and key event volunteers.

And, with a stroke of a pen (or a hit of "return"), my freedom to choose what is best for my own health has been taken away. Now I know what you are thinking: "Wait a minute, Julie! What about the health of all those other folks with CF at the meetings?"

JULIE DESCH

The Foundation's answer: "What others? There will be only one person with CF *invited* to any of our events, and we will determine who that will be." I shall subsequently refer to the Foundation's position as The New World Order.

My answer: Other adults with CF are free citizens with the mental capacity to decide for themselves if the risk of being exposed to me, or to Paul Quinton, or Beth Sufian, or fill-in-the-freaking blank, outweighs the benefits of going to a CFF function. If they deem the risk too great, they stay home. If not, they attend the meeting, and while we may share a knowing glance across the gigantic lecture hall as we recognize each other's cough, we likely will not hug or kiss, or indeed get anywhere near each other.

I propose that mine is the correct answer in a perfect world…or actually, in a Democracy that ensures the right to assemble, to free speech, and that forbids breeches of the Americans with Disabilities Act, and the Health Insurance Portability and Accountability Act of 1996. But I digress. In The New World Order, the CFF has decided *for all of us* that the Committee knows best. Now go play with your doll, little girl.

The reasoning given for this new mandate is given as:

Given the risks of person-to-person spread of CF pathogens within healthcare and non-healthcare settings, it is felt that

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TILLMAN *continued from page 9*

the formation of P. aeruginosa biofilms. It's also integral to stabilizing biofilms, so therapies have been proposed to alter P. aeruginosa's uptake and acquisition of iron to fight biofilm development in the lung. Because Fe(III) is commonly assumed to be the dominant physiologically relevant form of iron, therapies focus on blocking Fe(III) acquisition. Sputum samples were tested from a cross-section of 33 cystic fibrosis patients. Fe(II) was abundant in the lungs of cystic fibrosis patients, and it comprised a considerable amount of the total iron in each sample. Furthermore, sicker patients had greater quantities of Fe(II); and while Fe(II) concentration was significantly correlated with disease, the concentration of Fe(III) was not. Targeting both forms of iron might be more effective than targeting Fe(III) alone when treating P. aeruginosa.
http://tinyurl.com/pr88lvw

Genotype-Phenotype Study Defines Disease-Causing Versions of Cystic Fibrosis Gene

With over 1,900 mutations in the genes responsible for cystic fibrosis (CF), separating the harmful alterations form the benign ones has been a long undertaking for geneticists. Researchers now describe major progress in determining which mutations are which, increasing the number of recognized CF-causing mutations from 22 to 127. The new findings represent 95 percent of the significant variations found in the so-called cystic fibrosis transmembrane conductance regulator (CFTR) gene. Their analysis also included several dozen variants with either neutral or still-uncertain effects. The collection is expected to prove useful for understanding CF biology and targeting treatments to match mutant alleles

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DESCH *continued from page 10*

there are also risks of transmission of CF pathogens between people with CF who attend indoor events at the same time. While this risk is likely to be greater with epidemic strains of specific pathogens as described above, the risk cannot be quantified for specific microorganisms. Additionally, this risk is likely to be higher in small enclosed spaces, (e.g., inside a car or in a small conference room), than in a large meeting hall, but the risk cannot be quantified for specific indoor events. Furthermore, there are opportunities for individuals with CF to inadvertently have contact outside of the conference rooms (e.g., elevators, vendor booths, hallways). Thus, it is recommended that only one person with CF attend indoor events and that accommodations for non-face-to-face contact be made for others with CF such as Webcasts or teleconferences.

Perhaps it would be best if we each moved to our own separate little island or sanatorium? All right; enough sarcasm. Let me be blunt. Actually, there are NO data to support this draconian measure. Every article cited by the committee discusses cross-infection in one of three situations: 1) a health care setting such as a clinic or hospital, 2) the CF camps of old, before any attempts at cross-infection control were enforced--where kids with CF shared food, treatment rooms, tents, and were not even given basic hand hygiene advice (no offense intended, this was before we knew better), and 3) cases of siblings with CF living together. There is no specific evidence of cross-infection in a setting other than these three situations. This lack of direct evidence is likely why the committee used the phrase "it is felt" at the onset of their attempt to justify the new policy. A feeling is not scientific proof. My therapist assures me of this.

Another telling phrase is, "the risk cannot be quantified." Well, yes. This is why we design experiments and at least *try* to quantify reality before issuing a New World Order. Let us think for a moment about other risks that are unquantifiable but definitely not zero. There is a very real risk that a physician at a meeting might harbor MRSA in her nostrils, or could be transporting *B.cepacia* on a necktie that he wore in CF clinic the previous day. Should the CFF recommend that all physicians at their meetings wear masks at all times and wear a specific uniform deemed by the Foundation to be sterile? After all, one doctor could theoretically shake another's hand, accidently brushing across his tie (or her nostril with exquisitely bad aim), and take that MRSA or *cepacia* back to her or his own CF clinic. A risk? Yep. Likely? Nope. Is it really possible to eliminate all risks? No. Should we do everything in our power to reduce obvious risks but not infringe upon rights in doing so? Yes.

> "Should we do everything in our power to reduce obvious risks but not infringe upon rights in doing so? Yes."

Let me ask you a question. You are an adult, right? What do you do when you hear someone cough, or sneeze, or even look like a cough or sneeze is eminent? Do you rush to the person and make sure you are within six feet? Three feet? OF COURSE NOT! You are an adult with CF. You know to stay away from people who are sick, to wash your hands until your skin peels whenever you are near a sink, to cover your mouth and nose when you cough, to contain your secretions in a Kleenex and wash your hands (again) after you throw it away, to not handle serving spoons in a buffet line and, yes, to remember to wash your hands after using the bathroom. You also are aware, I am sure, that you and I should not shake hands, nor share an ice cream cone! How long have you been living with these rules of the road? I've been doing it for fifty-two years. I consider myself a very health-hygiene conscious person. We know this stuff. What we need as guidelines are completely and adequately addressed by another CF advocacy organization, CFRI, which states their current policy on infection control as:

1. Treat all individuals with CF with proactive hygiene protocols.

2. Practice vigilant respiratory and hand hygiene, especially after coughing, blowing the nose, disinfecting nebulizers, or doing treatments.

3. Reduce contamination of environmental sources, such as surfaces in common areas, by disinfecting frequently.

4. Avoid close contact between people with CF (no hugging, kissing, sharing food/drinks/phones, handshaking).

5. Individuals with CF should maintain a distance of 3–6 feet apart from each other.

These are simple and achievable precautions that would prevent nearly all scenarios where cross infection could occur.

You may wonder why this bothers me so much. A few months ago, there was a major skirmish in my local CF world caused when a boy at my son's middle school was asked to transfer schools when it became known to school officials that he had tested positive for CF on newborn screening. (Are any legal bells ringing?) Apparently, there was another family with two children with CF already enrolled in the school, and due to the *exact mentality of cross-infection paranoia* espoused by the CFF, the Palo Alto School Board freaked and tried to move the kid across town. I believe there might have been

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Needles

PHOTO BY DEREK POWAZEK

I am surrounded by physical pain,
Pain that pierces my body,
With every breath, with every touch, with every movement.
But I feel no pain,
For I have become stronger.
Strong enough to look pain in the face and smile,
To smirk at its witty desire to cause me discomfort,
to invade my space,
to destroy my inner being.
For only by tolerating pain, by befriending pain, can I survive.
After all, the emotional pain of this disease,
Now that hurts.

-A. Stenzel, 1997

"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...

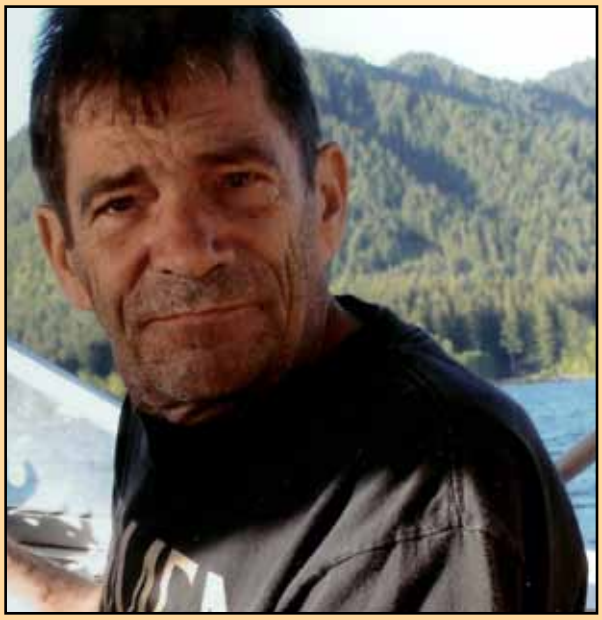
FROM LEFT TO RIGHT: PAUL QUINTON, ERIC GOODRICH AND STEVE SHEPHERD.

ANDREA EISENMAN DOING PHYSICAL THERAPY FOR HER KNEE WITH HER BALANCE BALL.

TOM MARTIN AND THERESA BOTEILHO IN WHITTIER, ALASKA ON A TOURING BOAT EXPLORING SOME GLACIERS ON PRINCE WILLIAM SOUND, IN AUGUST 2011.

LISA ZACCARIA

JIM CHLEBDA ON THE OTHER SIDE OF THE CAMERA, CAUGHT NEAR A FLOWERING CLARET CUP, A NATIVE CACTUS IN JOSHUA TREE NATIONAL PARK.



Remembering A Former Director Of USACFA

Patrick Hannegan

July 3, 1952 – July 7, 2013

Patrick Hannegan served on the board of directors of USACFA from autumn 1994 until spring 2000. During that time he was Vice President for four years. He was instrumental in the beginnings of USACFA and the first two organizational meetings were held at his house. Over the next few years, he assisted with labeling, stuffing and mailing of the newsletter.

Pat was born on July 3, 1952 in Portland, Oregon. He lived in and around Portland all of his life, except for a few years in Salt Lake City, Utah when he was young.

Pat was diagnosed with CF shortly after he was born. He was relatively healthy and was not hospitalized until he was 18. He was very active. He was one of those people who can fix almost anything. He loved to tinker and repair. He always had projects going.

He received a heart-bilateral-lung transplant at Stanford University Medical Center on March 7, 1991. His was the first such surgery, there, on someone who had diabetes. Surviving for 22 years after his transplant was impressive. He packed a lot of life into those extra years.

Eventually, as happens to many transplant recipients, the medicines caused damage to his systems and he was unable to survive. He died on July 7, 2013 at the age of 61.

He will be missed by all who knew him.

CREATIVE DISENGAGEMENT

Autumn's Early Arrival

By James Chlebda

This year *(like most, lately)* has been odd, weatherwise. Last year; same time; two words: *hot* and *dry* in the high desert. This year, thanks to three *(at last count)* tropical storms in the 'East Pacific' near Baja *(our West Coast),* we've been 'gently hammered' by monsoon rain these past weeks—I mean ½" to ¾" inches of rain in 8-10 minutes' time, accompanied by wind gusts, rolling peals of thunder and massive lightning bolts. Rainbows, intensely varied cloud formations, and distant clouds dumping solid walls of rain fill my viewfinder, with tropical sunsets and dramatic lightning displays at dusk and after dark. *(Note: CF Roundtable's deadline was mid-September for this Autumn issue, so there's a bit of a time flashback here.)*

The Fencepost Cactus out back soaked it all up. I thought I missed its bloom cycle when I traveled north to Stanford for a checkup; I'd returned and saw a load of dried flower husks strewn on the ground beneath the plant. But

yesterday, I was stunned to see over 25 new buds had erupted and at least half were about to pop! This cactus is also called *Night Blooming Cereus*, so I charged up the digi-cam and went out last night and early this morning for a serious look-see.

With the flash on, my first shots didn't focus well due to pitch darkness. *But* . . .I had a front row seat to palm-with-fingers-outstretched-sized

> "I was stunned to see over 25 new buds had erupted and at least half were about to pop!"

white satin blossoms topping each of the seven-to-nine-foot tall posts. I returned after the sun rose to catch some crisp shots before these all-too-brief blooms wilted. The bees had a field day; so did I. What a great way to start the countdown to the Equinox. I also noticed a number of shrubs around the region are now covered with purple-lavender flowers—so the bees and I have to explore what else has turned up from these late summer rains. Included here is one shot of this same *Cereus*, two years earlier, that I had used for a Christmas card. I had caught its bloom cycle on a clear, pre-dawn morn. More bees were out earlier than me that time 'round, which added more buzz to the images I'd shot back then. ▲

Jim is 55 and has CF. He resides on the edge of Joshua Tree National Park in California and can be contacted at: back40publishing.com.

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.

YOU CANNOT FAIL

The **You Cannot Fail** program is based on a saying that Jerry Cahill's parents shared with him at a very young age. This saying helped keep him determined to push through all bumps along his path.

You Cannot Fail is an inspirational launch pad that empowers people to discover and embrace their inner hero; to face the challenges of life with strength and courage; to meet each day with optimism; to live a life of creativity, purpose, and passion. **You Cannot Fail** collects, organizes, and shares individual's stories about specific aspects of their lives in order to motivate and inspire others to be the heroes of their own stories.

Visit: www.youcannotfail.com to share your story, inspire others, and to become a part of this official program of the Boomer Esiason Foundation.

Why It's Necessary To Follow the New Infection Control Guidelines

By Lisa Zaccaria

I'm a stickler for following the rules when it comes to dealing with my cystic fibrosis. I have heard and seen too much about cross-infection among CF patients. So any information that my doctor gives me and tells me to follow, I do it. In March of 2013, the Cystic Fibrosis Foundation mandated a new policy regarding infection control among CF patients: instead of three feet away, stay six feet away from each other.

This information immediately became the topic of much debate and still is today. One of the main reasons why the CFF mandated this rule is because they said, "There was increasing medical evidence of a greater risk that people with CF could spread destructive germs to others with CF and this may lead to severe or worsening lung disease." Still, many people with CF do not agree with this rule and many have said they refuse to abide by it. In doing so, they are risking their health and the health of others. I, however, agree with this new rule and welcome it.

> "I agree with this new rule because I have heard my friends' stories of their first-hand experience with cross-infection."

I agree with this new rule because I have heard my friends' stories of their firsthand experience with cross-infection. Years ago, a friend of mine who did not follow the three-foot rule, once it was instated, still "hung out" with his CF friends until he found out that he cultured Cepacia Dolosa, a severe form of Cepacia, from one of his CF friends who had no idea he was culturing it. He now regrets that he never followed the three-foot rule. I have also seen many teenagers and young adults not take this rule seriously, and I saw five of them all "hang out" with each other. No more than three months later, all five of them were back in the hospital, and all five of them cultured MRSA when they previously never cultured it before.

Another thing to be aware of is just because two CFers both culture Pseudomonas does not mean they are culturing the same strains of Pseudomonas. Over the years, I have heard doctors tell their CF patients to stop getting too close to other CF patients because they were getting sicker. The patient would always say, "But we both have Pseudomonas." The doctor would always reply, "It doesn't mean you both have the same strain of Pseudomonas."

What is also scary and what some CFers may not realize is the fact that you or your other friend with CF may be culturing something that has not yet come up on your sputum cultures. This puts you at a high risk of getting a bug that you never cultured before.

Although I understand and agree that cystic fibrosis is one of the most isolating diseases out there, I believe the risk of not following this rule is far greater than the benefit. Robert J. Beall, president and CEO of the Cystic Fibrosis Foundation states, "We understand that these changes may be difficult for many in our community. However, we want to be sure that we are doing all we can to reduce the risk of cross-infection among people with the disease. The health and well-being of people with CF is our top concern – it is at the heart of all we do."

I know the need to communicate and interact with others with CF is important. No one understands this disease, what we go through, and how we feel more than another person with CF. However, there are much safer ways of communicating and expressing how we feel, such as through Facebook, Twitter, blogs, and reading newsletters such as *CF Roundtable*.

There is a reason why the CFF instated these rules. There is a reason why the CF doctors are telling us to follow these rules. There is also a reason why, when in the hospital, before going in a CF patient's room, the doctors wear gowns and gloves. The reason is cross infection.

Just think about it. How would you like to be a CFer that is fairly healthy? You decide that you want to go and meet another CFer who you are friends with on Facebook. That CFer is culturing a superbug like MRSA or Cepacia but doesn't know it yet, or that CFer may be culturing a different strain of Pseudomonas or staph, or even a mycobacterium that you are not culturing. A few weeks later, after being in close contact with your CF friend, you culture it. You get sick and end up in the hospital. Your PFTs plummet. Your health declines. Was it worth it? ▲

Lisa is 35 and has CF. She is a Director of USACFA. Her contact information is on page 2.

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some coercion involved.

The kid, a sixth grader, was in his first year in Palo Alto and had just started to make friends. He had absolutely no symptoms and, in fact, had no definite diagnosis of CF, as his sweat test was negative. He was literally forced to leave the school and asked to transfer to another middle school, miles away. He and his mother were completely traumatized, and he was home-schooled until the courts had to settle the problem. He returned to his school only after a court order was issued overriding the school's actions, which were clearly illegal. Oddly, the CFF never commented on this case or came to the child's defense.

This is what happens when we are told that we are potential pariahs to each other and well-intended infection prevention measures grow into a New World Order fear. The kicker is that the three kids with CF genotypes at my son's school were certainly threatened more by coughing/sneezing virus-laden CFTR-able students and teachers than they were by each other. School boards in Palo Alto and elsewhere should be more concerned with universal infection precautions and less with segregation by diagnosis.

The now acclaimed Palo Alto case was very likely provoked by the Foundation's New World Order approach, as stated in the proposed recommendations for kids in schools:

The CFF recommends that people with CF attending the same school should NOT be in the same room at the same time. The CFF recommends education of school personnel on the principles of Infection Prevention and Control for CF so they can work with people with CF and/or parents (or legal guardians) to develop strategies to minimize contact between people with CF (e.g., assignment to separate classrooms, separation during other scheduled common activities including lunch, physical education, and recess).

So now, in addition to feeling the usual pressures/stressors of being an adolescent kid with a funny cough and a progressive chronic illness, the CFF would like us to enforce "CF segregation" in lunches, recess, sports teams, and classrooms. This based on feelings about unquantifiable risks.

A less emotional and much more scientific discussion of this topic appears elsewhere in this edition of *CF Roundtable*. This is not a simple problem with a simple answer. There is no question that attending a conference with others with CF might pose a risk. But I'm an adult with a (reasonably) functioning brain, as are you. I do not take segregation lightly, and I ask you to read with interest the article written by Steve Shepherd, Paul Quinton, and Eric Goodrich. ▲

Julie is 52 and is a physician who has CF. She may be contacted at: jdesch@usacfa.org.

TILLMAN *continued from page 11*

present in CFTR, when possible. It should also help in screening newborns for CF and determining the carrier status of individuals with variant versions of the gene. Since not all mutations cause disease, sequencing the DNA in both copies of the CFTR gene and finding an abnormality in one wouldn't determine if a person is a carrier for CF unless that abnormality causes CF.
http://tinyurl.com/njfakkd

Irish-led Project has Potential to Revolutionize Cystic Fibrosis Treatment

An Irish-led international consortium of experts has started a major project to develop personalized antibiotic treatment for cystic fibrosis patients during respiratory infections. The study will pave the way for more effective therapeutic regimes and ultimately contribute to the development of personalized CF treatment tailored to individual patients.
http://tinyurl.com/pnz9qmt

Scientists Discover Promising Potential Drug Target for Cystic Fibrosis

Scientists at the European Molecular Biology aboratory (EMBL) have discovered a promising potential drug target for cystic fibrosis. Their work also uncovers a large set of genes not previously linked to the disease, demonstrating how a new screening technique can help identify new drug targets. The only drug currently available that directly counteracts a cystic fibrosis-related mutation only works on the three percent of patients that carry one specific mutation out of the almost 2000 CFTR mutations. Starting with a list of around 7000 genes, the scientists systematically silenced each one, using a combination of genetics and automated microscopy, and analyzed how this affected the epithelial sodium channel (ENaC). They found over 700 genes which, when inhibited, brought down ENaC activity, including a number of genes that no one knew were involved in the process. Among their findings was a gene called DGKi. When they tested chemicals that inhibit DGKi in lung cells from cystic fibrosis patients, the scientists discovered that it appears to be a very promising drug target. Inhibiting DGKi seems to reverse the

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effects of CF, but not block ENaC completely. Inhibiting DGKi reduces ENaC activity enough for cells to go back to normal, but not so much that they cause other problems, like pulmonary edema.
http://tinyurl.com/om39yhc

New Avenue for Improved Treatment of Cystic Fibrosis. Combining Drug Targets May Prove Most Effective Way to Treat Disease

To better understand the difficulty of looking for a cure, or even effective treatment, one must understand the large and complex nature of the CFTR protein. It is made up of 1,480 amino acids strung together in five three-dimensional strands (called domains) that spin together and fold to act as building blocks for the CFTR protein. Although there are about 2,000 mutations associated with the CFTR gene, the most common mutation, known as F508del, found in 90 per cent of patients with the disease, involves the deletion of a single amino acid at position 508 in the CFTR protein. This single absence weakens the whole protein structure and renders it nonfunctional. The best hope for treating symptoms of cystic fibrosis at the moment is a drug called VX-809. However, this experimental drug is ineffective for the vast majority of those who suffer from the disease. That is because VX-809 seems only to restore inter-domain communication within the protein, but the domains within the protein remain weak. In cell cultures the F508del structural effect is not restricted to the domain where it is found. The mutation has negative effects on the other four domains of the protein as well, which compromises the appearance of CFTR at the cell surface. By combining VX-809 with chemical compounds that act as correctors on the domain containing the F508del mutation, the efficiency of the combination of drugs went up from 15 per cent to 60-80 per cent in cell culture models.
http://www.healthcanal.com/

In Memory

Patrick J. Hannegan, 61
Portland, OR
Died on July 7, 2013

Kathleen Harris, 70
Bowie, MD
Died on June 27, 2013

David Alden Lee, 51
Yardley, PA
Died on May 25, 2013

Immediate family members may send in the names of CF adults who have died within the previous year for inclusion in "In Memory." Please send: name, age, address and date of death.
Send to:
CF Roundtable, PO Box 1618, Gresham OR 97030-0519.
E-mail to:
cfroundtable@usacfa.org

TREATMENTS

Timing of Dornase Alfa Inhalation for Cystic Fibrosis. Ruth Dentice, Mark Elkins. Cochrane Reviews. Published Online: 5 Jun 2013

The current evidence derived from a small number of participants does not indicate that inhalation of dornase alfa after airway clearance techniques is more or less effective than the traditional recommendation to inhale nebulised dornase alfa 30 minutes prior to airway clearance techniques. Without strong evidence to indicate that one timing regimen is better than another, the timing of dornase alpha inhalation can be largely based on pragmatic reasons or individual preference with respect to the time of airway clearance and time of day.
http://tinyurl.com/psuv2vd

Extended-Infusion Cefepime Reduces Mortality in Patients with Pseudomonas aeruginosa Infections. Bauer KA, West JE, O'Brien JM, Goff DA. Antimicrobial Agents & Chemotherapy. (Apr 2013)

The clinical and economic outcomes associated with extended-infusion cefepime in the treatment of P. aeruginosa infections was evaluated. Cefepime extended-infusion provides increased clinical and economic benefits in the treatment of invasive P. aeruginosa infections.
http://tinyurl.com/oqdofzw

Inhalation Treatment with Glutathione in Patients with Cystic Fibrosis: A Randomized Clinical Trial. Matthias Griese, Matthias Kappler, Claudia Eismann, Manfred Ballmann, Sibylle Junge, Ernst Rietschel, Silke van Koningsbruggen-Rietschel, Doris Staab, Claudia Rolinck-Werninghaus, Uwe Mellies, Thomas Köhnlein, Thomas Wagner, Susanne König, Helmut Teschler, Hans-Eberhard Heuer, Matthias Kopp, Susanne Heyder, Jutta Hammermann, Peter Küster, Marguerite Honer, Ulrich Mansmann, Ingrid Beck-Speier, Dominik Hartl, Carola Fuchs, the Glutathione Study Group, and Andreas Hector. American Journal of Respiratory and Critical Care Medicine. Volume 188, Issue 1

The authors aimed to assess glutathione delivered by inhalation as a potential treatment for cystic fibrosis (CF) lung disease. Inhaled glutathione in the dose administered did not demonstrate clinically relevant improvements in lung function, pulmonary exacerbation frequency, or patient–reported outcomes. Glutathione delivery to the airways was not associated

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"You're Not Welcome" – The CF Foundation's New Ban

By Steve Shepherd M.P.H., Paul Quinton, Ph.D., and Eric Goodrich, M.D.

This spring the Cystic Fibrosis Foundation adopted a new infection control policy. First announced on the Foundation's Web site, the policy was prompted by growing concern that under some circumstances people with CF who harbor certain difficult-to-treat bacteria can transmit these bacteria to other people with CF. As a key part of that policy the Foundation will now ban any two or more people with CF from attending indoor Foundation events at the same time. To read the whole policy go to the Foundation's Web site, but the ban itself reads as follows:

> *At any CF Foundation-sponsored* ***indoor*** *event, meeting or office, including gatherings such as Foundation chapter committee meetings, only* ***one*** *person with CF may be present. This person will be designated by the Foundation in close consultation with event chairs and key event volunteers.* [emphases in original]

Months after posting the ban, the Foundation added a link to a list of 16 studies and reports that it said provided a scientific basis for the ban. The three of us have CF. Two of us are parents. We are CF greybeards: as old as the Foundation itself—or older. We remember the days of the "CF Camps," and at times we have each been involved in Foundation activities. We have each published our own research on CF. Paul has devoted his career to scientific study of the disease. And Eric has cared for both children and adults with CF—and seen some die.

It is from these perspectives that we have read the 16 papers presented by the Foundation in support of its ban. We've read dozens of others as well, and having done so it is our conclusion that imposing the ban may be the biggest mistake the Foundation has ever made.

Why?

Stretching the science

By now, almost everyone with CF knows that certain harmful bacteria can be passed from one person with CF to another. Two of the best known examples are the "epidemic" strains of *Pseudomonas aeruginosa* (such as the one first found in Leeds, England) and various members of the *Burkholderia cepacia* complex—often just called "*cepacia*." Also by now, most people with CF know that infection with these bacteria can be especially serious: the infections can be hard to treat, can leave you sicker than you were before, and can shorten your life.

The papers in the Foundation's list provide solid evidence for all this. But these facts alone don't tell the whole story. In particular, it is important to remember that just because a thing *can* happen, doesn't mean that it *will* happen or even that it's likely. For example, the researchers in one paper on the Foundation's list studied how far a person with CF could transmit germs by coughing or speaking. They set out culture plates on a table at evenly spaced, set distances from a person with CF who coughed or spoke. The results from tests on 42 people showed that in this scenario germs could travel as far as 6 feet. This is a well-performed, reasonable study and its results provided part of the evidence the Foundation used to justify the ban. But other evidence from the same study is equally important to consider.

It takes more than the movement of a germ from one place to another to cause an infection. Even without considering that culture plates don't have immune systems, the study's authors said that while their work showed it was *possible* for a person with CF to infect another person with CF as far as 6 feet away, the "probability was low." How low? The researchers set out a total of 336 culture plates in their study and of these only 4 grew germs; 332 did not. At the 6-foot distance, 2 of 84 plates grew germs. So while the study did show that germs *could* travel as far as 6 feet under the conditions tested, it also showed that in 82 cases out of 84 they didn't actually do so.

All the papers in the Foundation's list show these same kinds of probabilities: low probabilities for occurrence, high probabilities for nonoccurrence. Moreover, not one of these papers—*or any other*—demonstrates an infection caused by transmission of germs from one person with CF to another under the circumstances that apply in the places covered by the CF Foundation ban: public spaces, usually with room to spread out, where adults—most of whom don't have CF—gather for business or professional reasons, have learned to keep their distance, to wash their hands, to cover their mouths, and to behave with constraint. This lack of evidence for transmission in the situations covered by the ban suggests why the

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Foundation's Web site sets out the rationale for the ban in a string of *ifs*, *coulds*, *mays*, and *mights*. One small-probability event after another has been heaped together to justify a policy that itself has a low probability of preventing new illness (because in the settings covered there isn't much chance of transmission in the first place) but does have a high probability of doing harm—beginning with the damage it does to the rights and concept of adulthood.

Treating grown-ups as children

Half of all the people in the United States with CF are now 18 years old or older. Of course, it wasn't always this way. In 1955, when a group of parents got together to start what became the Cystic Fibrosis Foundation, adults with CF were unheard of. As a result, those parents created an organization to do what parents do: make the best possible decisions for their children. They considered their options, sized up the plusses and minuses of each, then chose a course they hoped would minimize the risks and maximize the benefits to their children.

Adults make their own decisions the same way. We get on an airplane knowing there are risks and that should events turn out badly the results will be dire. But we do so knowing also that the chances of a mishap are small, that the pilots are well trained, and that there are benefits to flying. We weigh these risks and benefits to make our choice: If we want to get somewhere fast, we fly. If we judge the risks to outweigh the benefits—as many people did after 9/11—we drive or stay home. Either way, adults have the right to make such decisions for themselves.

A faulty gene does not take that right away. Nor does it give that right to someone else. Just because the CF Foundation began as an organization used to making decisions for others does not mean that behavior should continue when conditions have changed. On its Web site the Foundation says it imposed the ban in the "best interest" of people with CF. But while the CF Foundation may credibly have been able to claim in 1955 that it—and it alone—knew what was in the "best interest" of people with CF, there are now in the United States 15,000 adults better positioned than anyone else to know and to decide this for themselves. Even so, the committee whose recommendation gave rise to the ban discounted this resource. That committee included doctors, scientists, Foundation officers, three parents, and *one* adult with CF—a former poster child and longtime Foundation employee. Effectively, adults with CF had no voice in the process that led to the decision that they were too dangerous to be around each other.

> "The committee whose recommendation gave rise to the ban included doctors, scientists, Foundation officers, three parents, and *one* adult with CF—a former poster child and longtime Foundation employee. Adults with CF effectively had no voice in the process."

Causing harm

The right to decide for yourself what is in your own best interests and to act accordingly is the hallmark of what it means to be an adult. Such decisions include the finding of an acceptable balance between the risks and benefits of going to a meeting where other people with CF may be in attendance, and when the CF Foundation takes that right away it undermines the value of the adulthoods it has worked so long to help make possible. Taking this right away tells both 18- and 60-year-olds that they are incompetent to make such a decision for themselves.

This message can harm a person's self-esteem. But it is not the ban's only such message. The ban tells people with CF that they are a source of contagion: that they should be fearful of people like themselves—and that they in turn should be similarly feared. And when an organization that professes to have the "best interest" of people with CF in mind labels people with CF unsafe to be around their own kind, it is easy to imagine that message simplified and absorbed by the general public as meaning that people with CF are somehow a risk and best kept at a distance as people to be shunned.

This is what happened early in the AIDS epidemic. Widespread fear among the general public of a deadly infection perceived as easily transmitted led to proposals for bans, quarantines, and restrictions on every individual within a group of people deemed potentially hazardous by the wider society. This, despite good evidence that HIV transmission only took place within a narrow set of circumstances of little relevance to most people. The public in its fear stigmatized an entire class of people and the resulting damage has taken decades to undo.

Finding a better solution

Neither the ban nor its likely fallout is necessary. And that fallout has already begun. Soon after announcing the ban, posts began appearing on the Foundation's Facebook page. Siblings felt the Foundation was forcing their separation. (If two people with CF couldn't be together at a Foundation event, didn't that mean they shouldn't be together anywhere?) Parents wrote to say they were glad the ban would protect their children. Adults wrote to say they thought the ban was wrong. And the parents wrote to denounce the adults for 'advocating for things that would shorten their children's lives.' (To which the answer is that nobody is advocating for anybody doing anything they think is dangerous.) Some wrote to say the policy had put them "in tears." And one young woman wrote of her anger and grief that her longtime sense of "being part of a team that is working to make the lives of CF patients better, longer, and more fulfilling" had been ripped away. "With this new policy," she went on,

I regret to say that I have never felt so isolated, singled out, betrayed, and ashamed of my CF. For the first time in my life, my CF is stopping me from doing what I want to do: help others with CF by being actively involved in Foundation meetings and events, and helping find a cure for this disease.

> "Just because the CF Foundation began as an organization used to making decisions for others does not mean that behavior should continue when conditions have changed."

For the CF Foundation to have inflicted this kind of pain is inexcusable. And needn't have been. Good science exists to support better alternatives. Where the effort has been made, the use of simple infection control practices has made possible even the revival of CF camps. Such practices include maintaining safe distances, frequent hand washing, and common-sense respiratory hygiene. CF-related organizations in both the United States and Canada have incorporated such practices into policies that encourage and enable the safe participation of adults with CF in their meetings, and the CF Foundation could—and should—do the same.

It just needs to try. ▲

Steve is 59 and has CF. You may contact him at: stevenlshepherd.com. Paul is 69 and has CF. He is on the faculty of the UCSD Medical School and of the new UC Riverside Medical School. Most of his academic research has been related to understanding abnormalities in CF. You may contact him at: pquinton@ucsd.edu or at: 619-543-2884. Eric is 57 and has CF. He attended medical school and then performed his residency in Family Medicine at UCSD. He has cared for patients with CF of all ages and stages of illness. For the past 17 years he has held the position of Volunteer Clinical Instructor at the UCSD School of Medicine. All three men live in San Diego, CA.

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MARTIN *continued from page 1*

debunked and untrue. Milk and meat companies want us to think that, so they advertise as such. Milk is specifically designed for a calf (cow) and not intended for human consumption. In fact, the milk protein removes calcium from the human body; this is the case with osteoporosis (cite: Dr. McDougall). It is better to get calcium from broccoli and other dark green vegetables. Lack of protein is another myth that has been propagated. In fact, there is plenty of protein in whole grains and vegetables, such as oats and broccoli. If one is to consider the animal kingdom, elephants and gorillas are all vegetarians and very large and healthy.

So the real question remains, "What are the real results of my 30-day vegan challenge as a CF person?" My BMI remains the same at '25' just above the normal weight range. My oxygen saturation went from 98 to 99, my PFT went up 7 points, and my cholesterol dropped to 119 from 155. My bike performance increased, as in climbing hills more quickly, as reported on "STRAVA" (App GPS for mountain bikers). The most important factor is I no longer have constipation issues, and I expect no more bowel blockages. I had a bowel blockage last November and that was the worst and most painful experience I've ever had - but no more! And, of course, I've really enjoyed eating vegan food and feel satisfied with what I've been eating. Honestly, I can't wait for my next meal. Dr. McDougall highly recommends a diet that is high in complex carbohydrates, with fruits and vegetables (The Starch Solution) and little to no oil or fat. I believe for the CFer, oil and fat are probably okay since it's difficult to gain weight. I tend to eat a lot of soy products which are very tasty and high in fat. To this day, I've been vegan for about three months, and I am feeling great and energized.

> "I decided to take a 30-day challenge and eat only vegan, no dairy and no meat of any kind."

When I consider the moral implications and destruction to the environment by consuming meat and dairy, as I've learned from watching a documentary called "Vegucated", my choice was clear. Other documentaries that have encouraged me are "Forks over Knives" and "Fat, Sick, and Nearly Dead."

Thanks, and to your health, Tom ▲

Tom is 45 and has CF. He received a bilateral lung transplant seven years ago. You may contact him at: tbmartin12@yahoo.com

TILLMAN *continued from page 20*

with changes in markers of oxidation, proteolysis, or inflammation.
http://tinyurl.com/mtmubhd

Pharmacokinetic Studies in Patients with Nontuberculous Mycobacterial Lung Infections. C. Magis-Escurra, J.W. Alffenaar, I. Hoefnagels, P.N.R. Dekhuijzen, M.J. Boeree, J. van Ingen, R.E. Aarnoutse. International Journal of Antimicrobial Agents. Published online: 09 July 2013.

Concentrations of anti-mycobacterial drugs are an intermediary link between doses administered and eventual response to the drugs. Few pharmacokinetic (PK) studies have focused on drug treatment for nontuberculous mycobacterial (NTM) disease, although a favorable treatment response occurs in just over 50% of patients despite drug treatment for a year or more. A prospective, descriptive PK study was performed to assess the plasma pharmacokinetics of rifampicin, ethambutol, clarithromycin, 14-OH-clarithromycin, azithromycin, isoniazid and moxifloxacin. The current study reemphasizes the relevant PK interaction between clarithromycin and rifampicin. This calls for a reevaluation of dosing strategies in NTM lung disease, as suboptimal drug exposure may contribute to inadequate response to treatment of NTM disease.
http://tinyurl.com/krlnrms

Surgical Management of Chronic Rhinosinusitis in Cystic Fibrosis: a Systematic Review. Jonathan Liang MD, Thomas S. Higgins MD, MPH, Stacey L. Ishman MD, MPH, Emily F. Boss MD, MPH, James R. Benke BS, Sandra Y. Lin MD. International Forum of Allergy & Rhinology. Article first published online: 9 JUL 2013

The objective of this study was to systematically review literature on the effectiveness of surgical management for chronic rhinosinusitis (CRS) in cystic fibrosis patients. For adult and pediatric CF sinusitis, endoscopic sinus surgery yielded clinical improvement as measured primarily by sinonasal symptoms and endoscopic findings. Most studies found improvement in symptom measures and endoscopic findings but no improvement in lower airway function after surgical therapy.
http://tinyurl.com/o3o3nle

Optimization of Anti-pseudomonal Antibiotics for Cystic Fibrosis Pulmonary Exacerbations: V. Aminoglycosides. David C. Young PharmD, Jeffery T. Zobell PharmD, Chris Stockmann MSc, C. Dustin Waters PharmD, BCPS, Krow Ampofo MD, Catherine M.T. Sherwin PhD, Michael G. Spigarelli MD, PhD. Pediatric Pulmonology. Article first published online: 2 SEP 2013

Intravenous (IV) anti-pseudomonal aminoglycosides (e.g., amikacin and tobramycin) have been shown to be tolerable and effective in the treatment of acute pulmonary exacerbations (APEs) in both pediatric and adult patients with cystic fibrosis. The aim of this review is to provide an evidence–based summary of pharmacokinetic/pharmacodynamic, tolerability, and efficacy studies utilizing IV amikacin, gentamicin, and tobramycin in the treatment of APE and to highlight areas where further investigation is needed. The literature does not support the routine use of gentamicin in the treatment of APE due to a lack of studies showing efficacy and evidence indicating an increased risk of nephrotoxicity. Further studies are needed to determine the optimal dosing strategy of amikacin in the treatment of an APE, and to further identify risk factors and determinants that influence the development of P. aeruginosa resistance with once–daily administration of tobramycin.
http://tinyurl.com/mfomc4l

FYI

Interval Exercise Training in Cystic Fibrosis – Effects on Exercise Capacity in Severely Affected Adults. Wolfgang Gruber, David M. Orenstein, Klaus M. Braumann, Ralph Beneke. Journal of Cystic Fibrosis. Published online: 17 July 2013.

The aims of this study were to investigate the effects of interval training (IT) on lung function power (P) and oxygen uptake (VO2) at peak performance (peak) and ventilatory anaerobic threshold (VAT) in CF patients who were unable to participate in a standard exercise program (SEP) and to compare these IT responses with corresponding effects in CF patients performing SEP. In summary, IT represents an alternative, effective and safe training regimen with patients with CF and severe lung disease, with a greater potential than SEP.
http://tinyurl.com/m43e6he

The Role of Respiratory Viruses in Adult Patients with Cystic Fibrosis Receiving Intravenous Antibiotics for a Pulmonary Exacerbation. C. Etherington, R. Naseer, S.P. Conway, P. Whitaker, M. Denton, D.G. Peckham. Journal of Cystic Fibrosis. Published online: 26 July 2013.

The aim of this study was to determine the prevalence of respiratory viruses during acute pulmonary exacerbations in adults and compare the severity of these exacerbations with non–viral associated exacerbations. Viral associated pulmonary exacerbations in adults with CF are associated with more severe pulmonary involvement and respond less well to standard treatment.
http://tinyurl.com/mcnjejr

Bordetella bronchiseptica in a Pediatric Cystic Fibrosis Center. Cynthia Brady, Patricia Ackerman, MahryaJohnson, John McNamara. Journal of Cystic Fibrosis. Published

Continued on page 26

online: 06 September 2013.

The authors describe the incidence and characteristics of B. bronchiseptica in the CF population. The results suggest that B. bronchiseptica may be more common than previously reported and may play a potential pathogenic role in CF.
http://tinyurl.com/knwpovt

Baby Bottle Steam Sterilizers Disinfect Home Nebulizers Inoculated with Bacterial Respiratory Pathogens. Dana Towle, Deborah A. Callan, Patricia A. Farrel, Marie E. Egan, Thomas S. Murray. Journal of Cystic Fibrosis. Volume 12, Issue 5, Pages 512-516, September 2013

Contaminated nebulizers are a potential source of bacterial infection but no single method is universally accepted for disinfection. The authors hypothesized that baby-bottle steam sterilizers effectively disinfect home nebulizers. All steam sterilizers were effective at disinfecting all home nebulizers. Viable bacteria were not recovered from any inoculated site after steam treatment, under any conditions tested. Steam treatment is an effective disinfection method. Additional studies are needed to confirm whether these results are applicable to the clinical setting.
http://tinyurl.com/l89dfyl

Cystic Fibrosis and Pregnancy in the Modern Era: A Case Control Study. Monica Ahluwalia, Jeffrey B. Hoag, Anas Hadeh, Marianne Ferrin, Denis Hadjiliadis. Journal of Cystic Fibrosis. Published online: 09 September 2013.

Pregnancy does not lead to immediate or medium-term adverse effects for CF patients.
http://tinyurl.com/onyldnf

CFRD

Insulin and Oral Agents for Managing Cystic Fibrosis-related Diabetes. Gary M Onady, Adrienne Stolfi. Cochrane Reviews. Published online: 26 JUL 2013

The Cystic Fibrosis Foundation recommends both short–term and long–acting insulin therapy when cystic fibrosis–related diabetes has been diagnosed. Diagnosis is based on: an elevated fasting blood glucose level greater than 6.94 mmol/liter (125 mg/deciliter); or symptomatic diabetes for random glucose levels greater than 11.11 mmol/liter (200 mg/deciliter); or glycated hemoglobin levels of at least 6.5%. This review has not found any significant conclusive evidence that long–acting insulins, short–acting insulins or oral hypoglycemic agents have a distinct advantage over one another in controlling hyperglycemia or clinical outcomes associated with cystic fibrosis–related diabetes.
http://tinyurl.com/k6h4goh

TRANSPLANT

Respiratory Infections in Patients with Cystic Fibrosis Undergoing Lung Transplantation. Leonard J Lobo MD, Dr Peadar G Noone. The Lancet Respiratory Medicine. Early Online Publication; 23 August 2013

Cystic fibrosis is an inherited disease characterized by chronic respiratory infections associated with bronchiectasis. Lung transplantation has helped to extend the lives of patients with cystic fibrosis who have advanced lung disease. Classic cystic fibrosis–associated organisms, such as Staphylococcus aureus and Pseudomonas aeruginosa, are generally manageable post–transplantation, and are associated with favorable outcomes. Appropriate viral screening and antiviral prophylaxis are necessary

Genetic Mutation Information Resource

Collaborators from several institutions around the world and the US Cystic Fibrosis Foundation are excited to announce that a new resource – CFTR2 – is now available for public use! This is the result of an international research collaboration to provide information about specific cystic fibrosis gene mutations to patients, their families, researchers, health professionals, and members of the general public. We hope that you will find the information useful.

The website is available at www.cftr2.org. Once you have reviewed the website, please take a few minutes to complete the user satisfaction survey located in the blue box "How can you help us improve the website?" in the "Quick Links" section of the left margin. Your responses will help us improve the website. Please feel free to contact cftr2@jhmi.edu with any comments, questions, or suggestions; but, please note that we are unable to answer any questions about the medical care of individual patients, since we are the research team that helped develop the website and not a clinical care team.

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TILLMAN

to prevent infection with and reactivation of Epstein–Barr virus and cytomegalovirus and their associated complications. Awareness of drug pharmacokinetics and interactions in cystic fibrosis is crucial to prevent toxic effects and sub therapeutic or supra therapeutic drug dosing.
http://tinyurl.com/kpaqzvm

Chronic Stenotrophomonas maltophilia Infection and Mortality or Lung Transplantation in Cystic Fibrosis Patients. Valerie Waters, Eshetu G. Atenafu, Annie Lu, Yvonne Yau, Elizabeth Tullis, Felix Ratjen. Journal of Cystic Fibrosis. Volume 12, Issue 5, Pages 482-486, September 2013

Baseline chronic S. maltophilia infection is associated with an almost three-fold increased risk of death or lung transplant in CF patients. It is still unclear whether chronic S. maltophilia infection is simply a marker of severity of disease and ultimate mortality or whether it is causally related to disease progression.
http://tinyurl.com/oesgusc ▲

Laura Tillman is 65 and has CF. She is a Director of USACFA and is the President. Her contact information is on page 2.

REMINDERS

- Please notify us immediately of any address changes. Returned mail wastes money and delays mailings.
- We would like to act as a referral source for active adult support groups. Please send us your group name, leader's name and phone number, number and age range of your members and geographical area covered, and we will add you to our referral list.
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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., 712 Main, Suite 2130, Houston, Texas 77005. Email: cflegal@cff.org**.
- You may subscribe at www.cfroundtable.com

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

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