CF Roundtable
A NEWSLETTER FOR ADULTS WHO HAVE CYSTIC FIBROSIS
WINTER 2015

Osteoporosis And Osteopenia, A Battle For People With Cystic Fibrosis

By Paul Feld

What are the similarities between osteoporosis and osteopenia, and how do you find out if you have either of these conditions? These conditions are similar, as they both refer to bone loss, but the difference is how much bone is lost. When you have a bone density test, you receive a "T" score. A "T" score is the difference between your bone density and that of a young, healthy adult. A score of zero means there is no difference between the two. A negative sign indicates your bones have less density.

A score between 0 and -1 is considered normal. A score between -1 and -2.5 is considered osteopenia, and a score -2.5 or greater is considered osteoporosis. The higher the negative score, the more likely the person is to get a fracture. For people with osteopenia, like me, the goal is to prevent one's condition from progressing to osteoporosis. One way I stay as healthy as I can be is to continue to exercise daily, and a broken toe, ankle or leg would certainly limit, if not stop, my normal daily exercise routine. My heart and lungs cannot afford this limitation.

> "For people with osteopenia, like me, the goal is to prevent one's condition from progressing to osteoporosis."

So how does one go about preventing bone loss? Really, there are two options. Both include increasing calcium within your body. The first is to use calcium supplements and the second is to increase calcium via your diet. There is some controversy about using calcium supplements. Some studies suggest there is an increased risk for heart disease when taking calcium supplements. Calcium supplements increase the risks for kidney stone development, while dietary calcium actually reduces the risks of kidney stones. You can get good dietary calcium sources from dark, leafy green vegetables, calcium-fortified juices, and beans, to name a few.

Osteopenia and osteoporosis are common in adults with CF. Age and body mass are predictive indicators of these conditions, while pulmonary function tends to be non-influential. Another study showed osteopenia

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EDITOR'S NOTES

Wow! It looks as if winter has hit most of the country with a vengeance. I hope you are surviving okay and that you are staying safe and warm.

This issue of *CF Roundtable* begins our 25th year of publishing. When we began, there were six of us, now there are about 19 of us who do the work of creating this newsletter. Some of us are Directors, others are columnists and all care about providing a forum for adults who have CF to be heard and to be able to share information. I've been volunteering for all 25 years and still feel it is worth my time. I hope you will consider becoming a part of this fine group of great people. If you are interested in participating, contact **Jeanie Hanley**; her contact info is on this page.

Now, on to the business at hand. In the last issue, we printed that **Jim Chlebda** died on September 22, 2014. That was incorrect. He died on July 22, 2014. We regret our error.

Next, we have three new Directors. We welcome **Laurel Avery**, **Chris Kvam** and **Klyn Elsbury** to USACFA. They will add some new dimensions to the board. Read about them on pages 28 and 29.

I hope you have read our cover story, written by **Paul Feld**. He writes about osteopenia and osteoporosis and the roles that Vitamin D and calcium play in them. These are important issues to discuss with your physician.

In "Ask the Attorney," **Beth Sufian** answers questions about Medicare and disability benefits, as well as Medicare Advantage Plans. "In the Spotlight" features **Aaron Cunningham** and his CF journey. **Julie Desch** introduces us to a different way to deal with stress, in "Wellness." **Mark Manginelli** discusses infertility issues and insurance coverage in "Protecting What Matters."

Our Focus topic is: Ways To Become A Parent When You Have CF. **Andrea Eisenman, Jeanie Hanley** and **Mark Levine** all wrote of their experiences with having children or not having children. The new column "Parenting" has another story about parenting that was written by a father who wishes to remain anonymous. **Isabel Stenzel Byrnes** uses "Spirit Medicine" to write of giving birth through writing.

"Voices from the Roundtable" has an interesting article from **Beth Sufian**. In it she shares information about helping to keep one's spirits up while hospitalized. She also updates the Kalydeco case in Arkansas. As always, **Laura Tillman** has compiled a wonderful array of news in "Information from the Internet." "Speeding Past 50" is filled with a variety of history, hopes for the future and talk of anniversaries.

Remember to check out the photos in the center of the newsletter. This is our "family album" and you can be in it, too. We love to receive photos of adults who have CF.

Until next time, stay healthy and happy.

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, Gilead Sciences, and Hill-Rom.

Information From The Internet...

Compiled by Laura Tillman

PRESS RELEASES

Lynovex Designated Orphan Drug for Cystic Fibrosis

NovaBiotics announced that the FDA has granted Orphan Drug designation to Lynovex (NM001) for the treatment of cystic fibrosis (CF). Lynovex has a dual antibacterial-mucoactive mode of action that aggressively tackles both of the major clinical features responsible for progressive lung disease in cystic fibrosis. Lynovex is active against drug-resistant bacteria as well as bacteria that are in biofilm form. It also reverses antibiotic resistance in bacteria to conventional antibiotics when used alongside these drugs. Lynovex is being developed as an oral tablet for acute exacerbations and as an inhaled dry powder for chronic use and maintenance. Lynovex is intended for use alongside existing cystic fibrosis treatments and potentiates their antimicrobial effects. A Phase 2a clinical trial for the oral form of Lynovex is already under way. Clinical development of the inhaled form is also anticipated to get under way in 2015.

http://www.empr.com/lynovex-designated-orphan-drug-for-cystic-fibrosis/article/371729/

Durham's Parion receives $3M to work on cystic fibrosis treatment

Durham drug developer Parion Sciences received $3 million from Cystic Fibrosis Foundation Therapeutics (CFFT) to continue work on its investigational treatment for cystic fibrosis (CF). This grant will speed up the timeline for a Phase 2 trial in which Parion will test its experimental drug, called P-1037, in patients with CF. Parion scientists designed P-1037—an epithelial sodium channel (ENaC) inhibitor—to block sodium channels on the airway surfaces. Blocking this channel promotes fluid secretion and re-hydrates the mucus layers. Hydration of mucosal surfaces restores airway clearance, reducing infection and improving lung function.

http://www.bizjournals.com/

Savara completes enrollment for AeroVanc, inhaled MRSA drug for cystic fibrosis, Phase 2 trials

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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**

Winter (Current) 2015: Ways To Become A Parent When You Have CF.

Spring (May) 2015: Transitions – Many Types Of Changes. (Submissions due March 15, 2015.) Transitions are all around us. Whether it's moving from pediatric to adult care, leaving home for college or other school, getting married, having children, buying a home, getting a transplant or any other transition, tell us how you handled it.

Summer (August) 2015: What To Expect Post-transplant. (Submissions due June 15, 2015.) Have you had a transplant? Can you share your post-transplant experiences to help others? Help others avoid pitfalls and trouble spots. Tell us how to handle it.

Autumn (November) 2015: Incorporating Work Into Our CF Care. (Submissions due September 15, 2015.)

ASK THE ATTORNEY

Answers To Readers' Questions

By Beth Sufian, JD

The new year has started and we have received many questions related to Medicare benefits and Social Security reviews of eligibility for individuals currently receiving Social Security Disability benefits and working part-time.

Nothing in this article is meant to be legal advice about your specific situation. It is meant only as information. If you have additional questions or need more information, please contact the CF Legal Information Hotline at 1-800-622-0385 or CFLegal@sufianpassamano.com. Please use this phone number or e-mail address to contact the Hotline. All calls are returned in two days. Please check your voice-mail and e-mail to see if we have contacted you, if you leave a message. Calls left for us with other organizations are unlikely to make it to us, so it is best to contact us directly at the above number or e-mail.

Q: I receive Social Security Disability benefits and I understand that I can work part-time and make a certain amount and still keep my monthly benefit check and Medicare coverage. What is the monthly amount I can make from part-time work?

A: In 2015 the monthly amount a person can make from part-time work and still be eligible for Social Security Disability Insurance benefits is $1,090. The monthly amount was increased by $20 on January 1, 2015.

However, individuals with CF should understand that Social Security has recently been instructed by Congress to scrutinize all individuals who receive Social Security Disability Insurance benefits to make sure individuals receiving benefits meet all medical and non-medical eligibility criteria. In the past six months, Social Security seems to have increased the number of eligibility reviews it conducts of individuals receiving benefits who are working part-time. In the past, the CF Legal Information Hotline has received one phone call a month from a person with CF who is being reviewed by Social Security. In the past three months, the Hotline has received 10 calls a week from individuals with CF who are having their benefit eligibility reviewed by Social Security. Most of the individuals are working part-time.

Social Security regulations allow a person receiving Social Security Disability benefits to work making up to $1,090 a month from part-time work. However, if a person is reviewed, Social Security can find the person no longer meets the Social Security medical eligibility criteria. Social Security can also find that the part-time work activity is so close to full-time work activity that it determines the person can engage in full-time work. In such a situation Social Security may terminate benefits. A person can appeal the benefit termination and present evidence to show he meets the Social Security medical eligibility criteria and provide evidence that he is not able to work full-time. The appeal process is long and could take as much as one or two years.

BETH SUFIAN

Many people with CF need to work part-time, making under $1,090, to have additional funds each month to pay for living expenses. In such situations it may be helpful to work Monday, Wednesday, and Friday for four hours a day. A person may also choose to work Tuesday and Thursday for four hours a day. This way the person with CF can rest in the intervening days. If a person is reviewed by Social Security, the person can explain their need to work part-time to have enough money for living expenses and explain that working four hours every other day still allows the person the time needed to perform time-consuming daily medical treatments and rest. There is no guarantee that this amount of work activity will prevent a person from having the benefits terminated, but it could make it easier to explain the ability to work part-time while still stating a person is unable to work full-time.

Working eight hours a day for three days a week, even if a person is making below $1,090 from the work activity, can result in a finding by Social Security that the individual is able to engage in full-time work.

Supplemental Security Income benefits (SSI benefits) is a program that has different part-time work rules and a different monthly amount that can be made from part-time work. The amount a person can make and still receive SSI benefits varies depending on the amount of SSI benefits a person receives each month. Individuals with CF who receive SSI benefits should make sure they understand the work rules for SSI and the deductions from benefits that will be made if a person on SSI receives income from work activity.

> *"Many people with CF do not realize that marriage to a spouse who has assets over the SSI asset amount will result in the termination of SSI benefits and Medicaid benefits."*

Q: If I get married will I lose my SSI and Medicaid benefits?

A: Marriage can impact the ability to receive SSI benefits. Many people with CF do not realize that marriage to a spouse who has assets over the SSI asset amount will result in the termination of SSI benefits and Medicaid benefits. If the spouse's monthly income from work activity or other income plus the SSI benefit of the spouse with CF is over the household monthly allowable income amount, then SSI benefits and Medicaid will terminate.

It is important to know the income and asset limits for SSI and Medicaid before getting married. If SSI and Medicaid will be lost after marriage, alternative insurance coverage should be identified before the marriage ceremony. The amount of co-pays and deductibles under a private policy that may be required for medications and physician visits should be assessed.

Most state Medicaid programs require no co-pays or deductibles for medication or professional services. Often a person who has had Medicaid coverage for a long time is surprised to find that his monthly cost share on a private insurance policy could be $500-$800 a month. Understanding the monthly cost share under a private insurance plan is important when determining the effect of marriage on a person's ability to access CF care and medication.

Q: I spoke to a broker who sells Medicare Advantage Plans to people who have Medicare. The broker said it would be a great idea to switch from traditional Medicare to a Medicare Advantage Plan because I would save money on my out-of-pocket costs such as premiums, co-pays and deductibles. What should I be aware of before I decide to switch to a Medicare Advantage Plan? If I join a Medicare Advantage Plan and do not like it, can I switch back to original Medicare?

A: Medicare Advantage Plans can sometimes provide cost savings to Medicare enrollees. Brokers who sell Medicare Advantage Plans are typically helping people over the age of 65 who have original Medicare and who may have good health and may not have complex medical issues. Of course a person with CF who has Medicare is typically under the age of 65 and is eligible for Medicare because the person is receiving Social Security Disability benefits. A person who receives Social Security Disability benefits becomes eligible for Medicare 29 full months after his date of disability, which is the date he became incapable of substantial gainful activity that Social Security defines as the inability to work making more than $1,090 from part-time work.

The main issue to be aware of with a Medicare Advantage Plan is that the plan will likely provide full coverage only for physicians and hospitals that contract with the specific Medicare Advantage Plan. If a CF Center or hospital is not a covered provider on the Medicare Advantage Plan, then services provided by the physician or hospital may not be covered at all or may be covered at a very low reimbursement rate. Some people with CF see many specialists in addition to their CF specialists. A person who sees a number of specialists would need to make sure that each specialist was covered under the Medicare Advantage Plan. Original Medicare should cover all physicians at a CF Care Center and all hospitals used to provide in-patient care.

Medicare Advantage Plans are paid a special monthly payment by the federal government to cover each Medicare beneficiary who enrolls in the plan. This is a very general description of how Medicare Advantage Plans are paid. For more information go to: www.medicare.gov. The Medicare Advantage Plans make money if the enrollee has low monthly health costs. Medicare Advantage Plans have denied coverage for expensive treatment and services that are needed by people with CF.

A person who chooses a Medicare Advantage Plan and is unhappy with coverage can switch back to original Medicare, but it can take 30-60 days for the switch to occur. There also

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SPIRIT MEDICINE

ProCreation Through Writing

By Isabel Stenzel Byrnes

We all die. The goal isn't to live forever; the goal is to create something that will. – Chuck Palahniuk, *Diary*

ISABEL STENZEL BYRNES

"With your lung function, I strongly advise against getting pregnant." Those were the words my doctor said to me three weeks after my wedding. My numbers continued a downward trend, and nearly seven years later, I received a bilateral lung transplant. A few months later, another doctor reminded me, "Pregnancy post- lung transplant is not associated with favorable outcomes." And, with a wonderful husband who sees screaming kids at the supermarket and groans, "That's why tigers eat their young!," adoption has not been an option for me. Now 11 years post-transplant, I'm considered a long-term survivor. I'm fully aware that raising a child with CF and post-transplant comes with its risks. My outspoken sister used to say, "I believe in the no-child-left-behind policy!"

So, the topic of this edition of *CF Roundtable* triggers some of my deepest defenses. I have four-legged children. I'm just happy to be alive. And to be an auntie for five beautiful girls. I've taken the unconventional route to procreation.

Humans are born with an instinct to breed. Charles Darwin would tell us that it's wired in our genes to find a "fit" mate, to generate offspring, to teach them and ultimately leave those offspring (or genes) behind when we die. Reproduction is our ego's final act; "me" and "I" are important enough to keep going in the form of descendants. The act of procreation is our purpose; it's what keeps the cycle of life going. On a spiritual level, procreation is what keeps love eternal—as long as it's passed down from one person to another, through the generations, uninterrupted.

I'd like to offer another form of parenting. This is a spiritual form of giving birth, and giving life to the world. This form doesn't require an egg and sperm, in vitro fertilization or adoption papers. This one only requires you, and only you, and an open mind and heart. What is this, you ask? Writing. Writing is a form of giving birth.

For some, having CF can be a confusing and lonely inner experience. Creative expression is one potential tool to help us make sense of a struggle like CF. Having CF is a series of losses—loss of ideal life, health, image, roles, function, opportunities, future—what we call a "normal" life. With all of this loss, there can be an impulse of creation that is yearning to be born. Art is eternal.

Writing is one powerful form of creativity. As human beings, we have evolved telling stories. Stories make sense of life. Stories shape our lives and tell us where we've come from, who we are and where we're going. Stories have characters, plots, conflicts, beginnings and endings. They also have heroes and heroines. These are the characters faced with difficult challenges and who make choices informed by courage, hope and perseverance to overcome them.

When we write, we become the narrator or teller of our story. Stories help us regain control of our lives. Writing links the emotional and creative brain—the right hemisphere—with the logical, analytic brain—the left hemisphere. This helps us connect words with feelings, which is the first step in mastering those feelings. We are also linking *past* memories with *present* thoughts and feelings, which helps us create a new story at different points of time. We all lost control when we were born with CF. We *do* get to have some control over how to live with CF; if we do our treatments and exercise, for the most part, we can live longer. For some of us, however, no matter how compliant we are, we still don't get to choose how the story unfolds. But herein lies the power of this form of procreation: we do get to decide *how* to tell the story. We have the choice to write about how we are becoming the heroes and heroines of our own stories.

Writing is good for our health. The work of psychology researchers like Dr. James Pennebaker has shown that writing down difficult thoughts and feelings, can change heart rate, blood pressure and cortisol (stress hormone) levels for the better. He has found writers who only write negative memories—called rumination—do not show these health benefits. Those who write only positive memories do not either—perhaps because they aren't being authentic. People who can construct a story, who can build a coherent narrative with positive and negative thoughts and emotions, seem to benefit the most. Using words such as "cause," "reason," "meaning," "effect" can show insight and a healthy shift in perspective. Being able to write from one's own perspective and then reflect on others' points of view, also seems to be a sign of healing writing.

I have been writing since I was a little girl. My mother used to give me journals for each hospitalization and say, "Here, write down your feelings." For many years, I mostly ignored her advice. I wrote a few lines here and there, like my journal entry at age 14: "Dear God, please give me one day free from coughing." Yet, when I got sicker in my early thirties, I went on disability and couldn't do much. But I found that I could still write. I wrote during aerosol treatments—in the hospital, in bed, at my desk, on the couch. I decided to write a memoir with my twin sister, and this goal kept me motivated to keep living. When my sister went into rejection just months before our book was published, she exclaimed, "I can't die! I've got a book coming out! I have too much s**t to do!" Thankfully, she had a second transplant and was strong enough for the book tour.

Writing proves that I've existed. Author Dorothy Allison said, *"I am the only one who can tell the story of my life and say what it means"* Writing about living with CF can help us see how well we've managed, how far we've come, how hard it has been, but somehow we've survived. Often being sick is embarrassing, even shameful. Writing gives us back our voices, to tell the truth about illness. Similarly, I've lost many of my friends to CF. By writing about my loved ones in detail—in scenes, in dialogue, in captured moments using senses like sights, sounds, smells, touch—just for this moment we are bringing them back to life on the page. In doing so, we are re-living our lives together with our loved ones. Remembering stories can even bring a smile to our faces as we write.

William Shakespeare said, "Give sorrow words; *the grief that does not speak whispers the o'er-fraught heart and bids it break.*" If you have ever lost a loved one to CF, I believe we survivors *are the only ones who can tell the story of their loved one and say what it means*. We have the power to capture who our loved one was and what mattered most about her life—and death. We can *continue* our loved one's story, just by writing it down. Then, we are confronting, head on, the darkest and most painful truths of their absence.

Some writing might evoke tears. Stephen Levine says, "Be strong enough to be weak." This process of moving through difficult emotions, over time, can leave you feeling lighter and relieved. The process of externalizing feelings and "emptying the garbage can"—dumping, cleansing, catharting the painful feelings and memories outside of ourselves—lets us examine them and gain perspective.

Writing is the best, cheapest, most portable and convenient form of therapy. Anyone can write. You may need to tame the voice inside that may be judging your creative impulses and what's on the page. Though it comes with vulnerability, being heard and understood can help you discover new aspects of yourself. I encourage you to share your words—your spirit—with others. Write a blog. Send your writing to family and friends; this encourages empathy and intimacy. Post on websites, or publish in newsletters (like this one!). Let the world hear about what you are going through. Writing the truth about living with CF allows you to become a teacher. No one is immune to illness; by writing your story, you are teaching others about illness and resilience. Sharing stories builds community. As CF patients, we are in a unique position to use our personal stories to educate the public about cystic fibrosis. That's exactly what we are all doing with *CF Roundtable*. In fact, the creator of the *Roundtable* and the former columnist for Spirit Medicine, Lisa McDonough, taught *me* so much about living with CF through her writing.

Publishing is only one outcome of writing. Most people keep their writing to themselves or share it with a select few. The creative benefits of writing exist regardless of whether you write for yourself or for others. Ana and I took the step from private to public storytelling. We wrote our book together, shaped the story, launched it into the world, tried our best to get it out there, and then, at some point, it took on a life force of its own. Our book is our act of creation. My sister is no longer alive, but her words can be read and reread as if she's still saying them today. Someday I won't be here, but the book will be left behind. The spirit of writing lives forever.

So, whether you are a parent or not, I hope you'll consider writing as a form of procreation. Like real parenting, this procreation requires courage, a sense of adventure, flexibility, humor and openness. Experiment for yourself how writing can support you. No one else could share your story exactly how you would. Writing honestly means opening up to all possible emotions. Take risks. Be real. Pace yourself. Keep going. Procreate. Write out "a child." Leave behind your voice. You will become your story's hero or heroine.

Isabel Stenzel Byrnes is 43 and lives in Redwood City, CA. The second edition of her book The Power of Two *(Univ. of Missouri Press) was just recently released. She leads writing groups in person and online.*

SPEEDING PAST 50...

This And That

By Kathy Russell

What a year this has been. My health has been good. So that makes it a very good year, in my book.

I had cataracts removed from both eyes and now I can see without glasses. To some people that would not seem like such a big deal, but for me it is tremendously big. I have been wearing glasses or contact lenses since I was 12. Over time, I had become increasingly more near-sighted. I could read without glasses, but I could not see any distance at all. As a result of that, my glasses had become increasingly thicker. Thankfully, the newer ultra-thin lens materials had made it possible for me to wear glasses that didn't resemble pop bottle bottoms. Still, they were getting thicker and less comfortable to wear.

Now, I am wearing ultra-lightweight reading glasses. Because of astigmatism (irregularities in my eyeball shapes), I have glasses that look like regular bifocals, but the upper portion is clear glass with only the astigmatism correction. What a change. I love it.

One thing about having the cataract surgery that seems so cool to me is that I am just like all of my friends of my age. This is perfectly normal for a woman in her 70s. Wahoo! I am normal! (At least in one way.) For the first time in my life, the health problems that I am experiencing are more in line with what my friends who don't have CF are experiencing. I like feeling less unusual.

Another way that I feel usual is that Paul, my husband, and I will celebrate our 50th anniversary in March 2015. We can't believe that 50 years have gone by so fast. Yet, it seems as if we always have been married. I guess that is just one of the ways that time warps, when you are old. Most of our friends have been married similar lengths of time. Two of Paul's cousins and their spouses are celebrating their Golden Wedding Anniversaries in 2015, too. How fortunate we all are to have survived so long together.

> *"For the first time in my life, the health problems that I am experiencing are more in line with what my friends who don't have CF are experiencing."*

KATHY RUSSELL

Recently, as Paul and I talked about our anniversary, we realized that we have been volunteering for USACFA for 25 years. We began doing the legwork for USACFA and *CF Roundtable* in February 1990. We researched banks for one that would give us access to checking without charging us any fees. We got our Post Office box and the needed permits. We researched printers to find one that would help us get started. We registered USACFA with the IRS as a charitable nonprofit organization. I am honored to have been there as the first Treasurer of the group and to still be there as Managing Editor. I feel that my time has been well invested.

Although the first newsletter didn't go out until November 1990, this issue starts our 25th year of publishing. I know that the four founders who have died—Joe, Connie, Ken and Larry—would approve of how the newsletter has grown. (Melinda still is a subscriber, so we know she approves, too.)

From the start, we wanted *CF Roundtable* to be a place where adults who have CF can write of their concerns and feelings without having to filter them to please a doctor, other healthcare worker, family member, teacher or advertiser. We will not print anything that is libelous, but we do try to allow each person to have his or her say—without censorship. Occasionally, someone objects to something that has been published, but most of what we print finds fans.

In some instances, a person will write to tell us how a particular article or subject resonated personally. We always are happy to know that something we have published has made a difference. We have all of our writers to thank for that. You, the readers, are our best contributors of information. You are what makes *CF Roundtable* work.

In the beginning, we had three goals, which were: 1) to provide a forum for adults who have CF, 2) to sponsor conferences where adults with CF could get together to share information, concerns and ideas, and 3) to facilitate support groups. With this, our 97th issue, we still are accomplishing the first goal. *CF Roundtable* is a forum for adults who have CF. More about that, later.

In 1999 and 2001 we sponsored conferences for adults who have CF. They were well attended and well received, but we no longer are able to mount such gatherings. With the enhanced security measures, since September 11, 2001, it is much more difficult for our speakers to fly in, speak and go back home all in a single day, as they used to do. Thus, it is more difficult to get the speakers that we would want. Also, many physicians do not want their patients who have CF to gather where others who have CF will be. Even with stringent cross-infection-protection measures, there still is a risk of sharing "bugs" at such gatherings.

Support groups are frowned upon now, too. That makes me quite unhappy because that support is so important to us. I have talked with people who never had met anyone else who had CF and needed that connection to help adjust to where their lives were taking them.

I remember one woman who told me that she put on her name tag at a conference we held and left it on for her trip home. She said she then transferred it to her pajamas, because she felt she "belonged" for the first time in her life. I understand what she means. The conferences and support groups gave us a chance to be normal in a group of similar people. Those who always have been similar to their friends cannot really understand what it is like to always feel different from everyone.

So that leaves the third original goal of USACFA—provide a forum for adults who have CF. For the past nearly quarter-of-a-century, USACFA has published *CF Roundtable*. The newsletter has changed over the years. At first, it was a 12-page newsletter with no color added. We requested a donation of $10 per year to help cover the costs of publication. Now, it is available free-of-cost to any adult who has CF. Also, it is available online.

Gradually, we enlarged the size of the publication to as many as 44 pages and we added color photos. The center section of the newsletter affords adults who have CF the chance to have photos of themselves published in full color. We love to share those photos with our readers.

In each issue, on page three, we list suggestions for topics on which people may want to write. We call them Focus topics. For instance, the next Focus topic is "Transitions – Many Types Of Changes." Most any of us can relate to having to make changes, whether in our medical care, our housing, our schooling or just in life.

Of course, these are only suggestions and people may write about any CF-related topic that will be of interest to our readers. We also love to receive original cartoons, artwork and poetry that is done by adults who have CF. If you have a question about any aspect of CF, we are interested in those, too. Don't worry about what kind of writer you are. We are happy to work with you on an article.

USACFA is an unusual organization because there are no paid employees. All of the Directors and columnists are volunteers. (We always are looking for new volunteers.) All the donations that we collect go into the production and publication of *CF Roundtable*. You know that the money you donate will be used only for keeping this newsletter going. That is quite a return on your money.

We always are happy to hear suggestions from our readers. If you have ideas on how we can make *CF Roundtable* better, please let us know. Also, if there are topics about which you would like to read more, let us know and we will try to accommodate you.

Now I'm going to snuggle my achy, old body into my favorite chair and enjoy not having to go out in the winter weather. I wish you warmth, good health, happiness, love and laughter in 2015. ▲

Kathy is 70 and has CF. She is Managing Editor of CF Roundtable. Her contact information is on page 2.

In Memory

Susan Jeanne LeBoeuf, 62
Marriottsville, MD
Died November 2, 2014

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

WELLNESS

Combating Stress With Mindfulness

By Julie Desch

Since I traversed a unique path to motherhood, instead of writing about that, I am going to focus on stress for this issue of *CF Roundtable*. After all, motherhood and stress are (ahem) related, so it works for me.

Stress is not a lighthearted topic, but given the recent findings of the international TIDES study (The International Depression Epidemiological Study), I think it is important that we talk about stress and the common effects of mismanaged stress—namely depression and anxiety.

The TIDES study spanned 154 centers; 6,088 patients with CF and 4,102 parents. This is a very large sample size, and the statistically significant findings are eye opening. Specifically, there are elevated signs of depression in 10% of adolescents with CF, 19% of adults with CF, 37% of mothers and 31% of fathers (of children with CF).

The consequences of depression are decreased adherence to our very complex medical regimen, disrupted family function, diminished quality of life, difficulty with sleep, impaired appetite, poor energy and a weakened immune system. If this is not bad enough, I'm sure you can come up with a few more reasons that depression sucks.

The findings regarding anxiety in the CF world are worse. Elevations in anxiety were found in 22% of adolescents, 32% of adults, 48% of mothers and 36% of fathers.

Overall, these findings show the prevalence for both depression and anxiety in the CF community is two to three times greater than general community samples. Of course, both depression and anxiety are the result of complex factors including genetic, environmental, psychological and developmental factors. But, clearly, at the heart of environmental factors is the stress caused by living with CF. Knowing about the chances of a shortened life span is stressful. Not being able to do the "normal" things your peers do is stressful. Trying to fit into 24 hours all that needs to be done daily to manage your illness is stressful, because life doesn't stop just because you have to do treatments and occasionally go into the hospital. You still have to deal with "normal" life stress. And of course, knowing that even when you do everything right, the outcome often is out of your control is stressful.

All of these stressful events are "chronic" stressors, as opposed to "acute stress" such as being chased by a hungry tiger. We have evolved to get over acute stressful events (as long as we don't keep re-living the experience). But chronic stress is a different animal—no pun intended. Chronic stress wears on the body, physically and mentally. It always is there; ready to ruin your day if you let it. Hence the findings of the TIDES study.

JULIE DESCH, MD

So far, this has been quite a bummer of an article, and I'm sorry. But there is good news. There are quite a few things that are very effective for managing chronic stress. I've written about some of these before, namely getting daily exercise, proper nutrition and sleep, and finding time to relax and engage in activities with the people you enjoy being with on a regular basis. There are also very helpful medications when these lifestyle habits are not enough. There certainly is no shame in needing additional medical attention for depression or anxiety.

But in this article, I'd like to focus on a technique that I have found extremely beneficial for handling life with CF with a modicum of balance and even occasional equanimity. Mindfulness meditation has been a practice I've used on a fairly regular basis for over 20 years.

I took my first eight-week course in "mindfulness-based stress reduction" (MBSR) when I was in my mid-thirties, very early in my career as a surgical pathologist. For some reason, up until this point I had not had major lung complications from my CF. But with the stress of a new job, a significant commute and the necessarily busy schedule, my health began to decline. The reality of having a lung disease hit me square in the face, and I was looking for ways to help deal with it.

I saw a sign for the eight-week meditation class at the hospital where I worked, and signed up. This was one of the better moves I've made in my life, as I've benefitted from that class for the last 20 years. The practice I learned has helped me navigate through illnesses, upsetting sputum culture results, losing friends and another sibling to CF, losing my parents, and generally watching my health slowly decline. I won't say those things have been easy, but becoming familiar with that place beyond my mind and body that never changes has proven immensely helpful.

> *"Areas of the brain associated with the control of empathy, emotions and compassion grow, while areas involved in anxiety and stress shrink."*

That first class also planted a seed in my mind, though. I began to think that if it could work as well as it did for me, then maybe others in the CF community would benefit as well. This seed began to sprout about five years ago, when the opportunity to train as an MBSR teacher landed in my lap. I had a friend who had done the teacher training and, as a result, she and I began to teach a community class in mindfulness, which was a blast. That was when I knew I needed to pursue the idea of bringing MBSR to the CF world.

A brief word about MBSR is in order here. The class is the brainchild of Dr. Jon Kabat-Zinn, a Ph.D. in molecular biology who also happened to be a Buddhist meditation practitioner. He knew the practice of mindfulness would benefit sick people and, in 1979, began to ask his colleagues at the University of Massachusetts Medical Center to send him their toughest cases, the people for whom they had no answers. People with debilitating chronic pain, untreatable cancer, horrible anxiety or terminal diagnoses soon began showing up at his door. Of course, he knew he couldn't begin to preach Buddhist theory…this was a hospital, after all. Somehow, he had to secularize what he did every day. He needed to create Buddhist meditation without Buddhism.

So Kabat-Zinn came up with an eight-week program where patients met as a group once a week to learn several different meditation techniques as well as practice gentle yoga. They also talked about ways of coping with reactive states of mind, and learned how to practice being mindful in everyday life. They were given homework of daily meditation, using guided meditation tapes provided by Kabat-Zinn.

An amazing thing happened. Terminal illnesses weren't cured, of course, but people learned how to cope and enjoy what time they had left. Some people had pain reduction, but almost all improved the ability to tolerate their pain. Depression and anxiety lessened. Ever the scientist, Jon Kabat-Zinn collected the data and began to publish.

Now, there are thousands of published papers on the benefits of mindfulness. MBSR programs are offered in hundreds of hospitals and community centers internationally. The science is fascinating. It appears that just an eight-week intervention including meditation and gentle mindful movement at home, combined with the weekly group practice, actually physically changes the structure of the brain. Areas of the brain associated with the control of empathy, emotions and compassion *grow*, while areas involved in anxiety and stress *shrink*. And these changes correlate with what patients report in numerous psychological tests.

Research, then, supports what I have discovered directly: Mindfulness meditation can benefit those of us with cystic fibrosis by changing our brains in ways that foster emotional balance and self-compassion while reducing the ever-prevalent problems of depression and anxiety.

While I will begin to offer MBSR online with the support of CFRI this spring, please don't wait to experience for yourself how this technique might help you. There are MBSR classes offered in hospital and community centers nationwide. Google "MBSR" to find a class that might be starting near you. Or, if you aren't the group class type, guided meditations are available from many different sources, many free of cost. A great online resource for free meditations is at the UCLA Mindfulness Awareness Research Center (http://marc.ucla.edu/default.cfm).

A final word of advice: meditation is a practice that may feel very awkward and discomforting at first. You will fight sleepiness. You will doubt that it is working. You will wonder if you are doing it "right." You will want to give up and go get coffee. Your mind will wander off a thousand times. Please persist. Set aside a short time every day…even five minutes. Eventually, it will grow on you. You might even want to sit longer. You will learn a lot about what is less than skillful that your mind does, and this will prompt more healthy coping with life's difficulties. It is worth the investment. You are worth the investment. ▲

Julie is 54 and is a physician who has CF. You may contact her at: jdesch@usacfa.org.

FOCUS TOPIC

WAYS TO BECOME A PARENT WHEN YOU HAVE CF

Meant To Be

By Jeanie Hanley

I became a parent first and a patient with CF second. My three biological wonders are Kevin, Maria and Jessica and were 5 years, 1½ years and 4 months old respectively when I was diagnosed with CF. When I became a parent 25 years ago, I wasn't diagnosed with CF yet even though I had bronchiectasis and sinus disease, including multiple bronchoscopies and sinus surgeries—much more than the average non-CF bear. My sweat chloride was normal so, at the time, that ruled CF out. Soon after my third child was born, I was diagnosed via genetic testing.

I feel very fortunate that I didn't have to ponder the questions that so many with CF do as to whether to have children or not, IVF, adoption etc. Who knows what my husband and I would have decided if I had known for sure that I had CF at an early age. After all as a pediatrician and allergist, I had plenty of beautiful

JEANIE HANLEY

kids that I cared for deeply. But would they have been enough for me to not have children of my own? I had nearly 15 nieces and nephews when Kevin, my first, was born and was godparent to three of them. Would that have been enough?

These are questions to which I will never know the answer, but I do know this: What happens to us is usually meant to be and is just what we need to learn and grow in this life. I needed to have my three children so that we could help each other grow and mature as individuals. We have learned so much from each other. If I hadn't had them, then I would hope that I would have felt the same way – that it wasn't meant to be and that I just didn't need my own biological children to learn whatever it was I needed to learn in this life.

After becoming a parent, I had to make some changes once diagnosed. Up until Jessica, my last, was born I was using inhalers and many medications, but not on a regular basis. After the CF diagnosis, I followed a daily routine of inhaled medications and airway clearance techniques. And for the most part ever since, I've adhered to at least a twice-daily schedule (although the medications and airway clearance techniques have changed).

I have to say that the routine of my breathing treatments in the family setting has never been mundane. As babies, the kids crawled and babbled around me, sat on my lap and later did their homework around our family table when I did my treatments. We watched TV – albeit very loudly sometimes, sang songs mostly just to hear my vibrating voice (from the percussion vest), or did arts and crafts. I was able to sit and listen to what was happening at school and in their lives and observe them. They knew they had my full attention when I sat down to my treatments.

My routine was incorporated into my kids' routine and ended up setting a good precedent for excellent study habits that continued through college. They finish studying, classwork and the like as soon as they come home, so they can still have their play time – yes, even in college.

Because my kids have not known life with me and my treatments to be any different than the norm, they have never looked at my treatments as strange. Even when they were older and learned that no other parent they knew had anything resembling my routine, they were never embarrassed when their friends came over and I was sitting there doing my treatments.

> "Because my kids have not known life with me and my treatments to be any different than the norm, they have never looked at my treatments as strange."

Only twice over the span of now many years can I remember one of their friends being stunned at having seen me in my finest CF regalia. My son or daughter gave a quick explanation and life, or in their case, play went on. Many of their friends would enter my CF sanctuary at the family table and have a chat with me, again, knowing they had my full attention too.

As my husband and I are becoming empty nesters, I can reflect that parenting has an undulating quality, as do so many things in life. It has its ups and downs, challenging and easy-going times, sickness and health and periods of major internal growth followed by rest periods. The one constant for a person with CF is that we must take care of ourselves so that we handle whatever we're presented with in the healthiest state possible. If I felt too ill – going to the hospital for two weeks to recharge was better than being half-there for my kids and husband. I constantly have had to sacrifice some time to make sure I can give quality time to my kids when they were younger and even more so now, as adults. So much of parenting is about sacrifice, but willingly, and usually happily, made. ▲

Jeanie is 52 and has CF. She is a physician who is a Director of USACFA and is the President. Her contact information is on page 2.

FELD *continued from page 1*

and osteoporosis are common findings (greater than 50%) in a heterogeneous population of adults with CF. Patients at most risk are those with severe disease and those who have used corticosteroids.

A combination of calcium and vitamin D are critical in keeping bones both strong and healthy. You can get vitamin D from sunlight, food and supplements. Sunlight is best, as your body can store vitamin D from the sun for later use. Foods are okay but not many foods contain a great deal of vitamin D. Supplements will work well too, if your body can metabolize them well.

Personally, since I have had a lung transplant, sunlight is a poor option because I easily develop skin cancers. A solution with even a very small SPF (such as 15) reduces the UV rays needed to store vitamin D by 95%. So this is not a good solution for me.

The best food solutions are wild fish and salmon. While I enjoy eating those, I don't get nearly enough to fulfill my vitamin D needs. So I use supplements and am now taking up to 5,000IUs daily, which is a very high dosage.

My most recent vitamin D result is 22. The normal range is 30 – 100. So, there is a hidden problem that we have yet to find. I keep plugging away to reach a result of 30.

My recommendation is for all who have CF to get their bone density checked annually and take appropriate corrective action if needed. ▲

Paul is 57 and has CF. He is a Director of USACFA. His contact information is on page 2.

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

Andrea Eisenman, 50
New York, NY
November 28, 2014

Brandi Elliott, 23
Topeka, KS
May 24, 2014

Wedding

Johanna and Philip Libbert
Richland, IN
25 years on April 8, 2014

NEW BEGINNINGS

Johanna Libbert, 48
Richland, IN
Bilateral lung transplant
October 1, 2014

WAYS TO BECOME A PARENT WHEN YOU HAVE CF

If Only I Knew Then...

By Andrea Eisenman

When I was growing up in my apartment building, I played with other young kids my age. We all delighted in playing "house" at each other's apartments. We took turns being the mommy, the daddy (we were all girls), and the kids. My best friends were three sisters: Kim, Kerry and Kathy (named before the Kardashians made it chic to spell every child's name with a K). They lived upstairs and I loved going up to their place and being part of their busy household.

Kerry was my best friend and closest to my age. She was the bossy one and usually played the mom. We usually played that we had three or four kids each, having one was just not an option. Me being an only child, I concurred with this. I always wished I had a sibling and so, I vowed that when I had kids, I would have at least three—modeled after my pals who lived upstairs. But also, there was never a thought in my mind that I would not have children. It was just what one did when one became an adult, right?

Yes and no. At that time, when I was about 6-12 years old, I was blissfully unaware of what having cystic fibrosis meant regarding starting a family. My childhood was pretty normal to my recollection. I played with other kids, went to school, did homework, did what my peers did. But I also did twice-daily Mucomist inhalations (that smelled like rotten eggs, aka, Puke-o-mist) to help clear my lungs of mucus. I took several enzymes called Viokase before meals, up to 14 at times. These were days before Pancrease, Creon etc. And I also took prophylactic antibiotics orally.

Then I started hearing statistics about the median age of survival for people with CF (roughly my age until I made it into my 30s) and how it was unsafe and "not allowed" by CF centers for those of us who made it into adulthood to have children. I was no longer naïve about what CF meant regarding being equal with my peers.

ANDREA EISENMAN WITH HER DOG, ERNIE.

As I went through my anger and rebellious phase for many years, I just shrugged off having my own family. In my late teens and 20s, I figured I would be lucky to live until 25. Looking back, had I known I would live to be 50, I might have decided that having a child was something I could have done. But always feeling like I was living to the age of life-expectancy, I was not willing to bring a life into this world, to only leave too soon. Of course, no one knows how long they will live and cannot plan accordingly. People without a chronic disease can die suddenly, without warning. But I knew, most likely, I would die from complications from CF. In my 20s, I no longer was so healthy. My PFTs were in the 30s and my parents were told when I was 23 that I had six months to live due to three successive exacerbations of pneumonia.

I guess I felt it was better to not plan on having kids in my condition; it was not fair to a child. And it was not like I was married or had a serious partner. Even with adoption, I was not sure I could handle being responsible for another life when mine was so tenuous. My daily regimen involved a lot of self-care. Would I have time to care for another being, without infringing on my own health? Doubtful.

This led to my many adoptions of dogs throughout my life. At first, it was an experiment. Like, can I handle this? Will I make a suitable dog owner? I had always loved dogs but we always had cats as they were easier, especially living in New York City. Having to walk a dog several times a day might have been too much. My mom and I shared this experiment with our first pooch from Bide-A-Wee. We had no idea what we were doing and so, basically, Tony called the shots. He lived a long life with us and gave us years of laughs and enjoyment. I hope it was mutual.

Tony died three months after my grandmother passed. It was almost too much to bear. We got another dog almost immediately, as the loss of both my grandmother and our beloved dog overwhelmed us. We got Max, another shelter dog.

Then, in my 30s, I was living with a boyfriend with whom I had been for about four years. We adopted a dog together. Her name was Sadie and she was a lot of work because she had separation anxiety. This was understandable, as ours was her third home and she was only about six months old. So, I worked with a behaviorist who told me she needed activity to calm her down. I exercised her in the morning and learned to occupy her with toys that kept her busy while my boyfriend and I were at work.

Soon after this, as my health was in serious decline, I went on disability and moved back in with my mom. I had been listed for some time for a bilateral lung transplant. From NYC, we moved to my grandmother's old house on Long Island. It was easier to handle both dogs there, rather than walking them on the streets of Manhattan. We would just open the door and they did their thing. But then all of a sudden, Max died. We decided to wait until after I had a transplant to see if we could handle another dog. My care was time-consuming from waking to evening. Eventually, we adopted Molly, a long and lanky hound to keep Sadie company. That was not so successful with Sadie.

After a few years, I moved back to my old apartment that my mom and I had shared. My mom stayed on Long Island with Sadie and Molly. Sadie seemed to like it out there better than living in an apartment (wise dog). I felt she should stay with my mom. But I missed having a dog around. At first I helped a friend take care of hers; then I decided to get my own. I had talked to many people about getting a Boston terrier because of their personality. I tried to adopt one from a rescue, but because I lived in NYC, no one felt I would care for a dog well enough. So, I bought one from a breeder, which went against all of my beliefs. I had always gone to shelters.

Now I have Ernie. Sadie died six years ago and it was the most heartbreaking death of a pet I ever experienced. Even though she was not a person, she had developed such a personality and I felt she was so attuned to me and my mom. She had been with me through my sickest period and was always comforting me. When my mom and I did CPT, she was there on the bed. My mom clapped my back and I clapped Sadie's. When I was healed after transplant surgery and able to swim, she sat by the pool and watched. Even before my surgery, when I could swim in the bay, she swam next to me for almost half a mile. Sadie kept us busy, too. We had to play catch or kick a toy with her. We had been through so much together. I still cry when I think of this loss.

Having dogs has not been the same as having my own or even adopted children, but it has to be as close as I have come to loving another dearly and taking care of them to the best of my knowledge. I have enjoyed their presence immensely. They have and continue to enrich my life. Ernie is a comedian who, just by a look, can make me smile.

Making it to 50 has been an amazing milestone for me. One I never dreamed possible. And while I sometimes wonder whether I made the right decision about not having kids, I might not have made it this long had I adopted or chosen to get pregnant. As I will never know, I just have to accept that I make a pretty good doggy-mamma. ▲

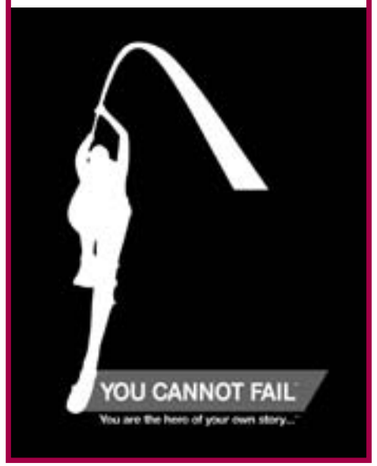
Andrea is 50 and has CF. She is a Director of USACFA and is the Executive Editor of CF Roundtable *and Webmaster. Her contact information is on page 2.*

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 individuals' 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.



FOCUS TOPIC

WAYS TO BECOME A PARENT WHEN YOU HAVE CF

My Own Modern Family

By Mark A. Levine

Twenty years ago, after graduating from college, I started working full-time. I was 24 years old and had just moved 700 miles from home to a city where I knew only two people. I found a good CF doctor and I started my life. I did not know what was in store for me, but I had a plan—work hard at my job and become involved in activities that would allow me to meet people.

Long term, I knew I wanted to meet someone to share my life with and start a family. However, at 24 I was not thinking that far ahead. Looking back, I am happy that I did not overthink things. I could have talked myself into dating only women who would be happy with adopted children or limited my search to women who already had kids. Since the option of having children in conventional ways was unlikely, I decided to let life unfold naturally.

And quite frankly, I got lucky. I met Joelle who came bundled with two awesome children, ages six and four. Having just turned 31, I initially thought I was too young to meet someone with kids. But the more I got to know Joelle, as well as Brooke and Adam, I realized that this was a true blessing. Although the children's biological father lived four hours away by car, he was present in their life, very responsible and a good influence.

> "Since the option of having children in conventional ways was unlikely, I decided to let life unfold naturally."

But I got to be a dad too, almost from the beginning. I missed first steps and first words, but I also missed not sleeping through the night and changing diapers. I taught the kids how to ride a bicycle, went to baseball games and the daddy-daughter dance. I took the kids to temple weekly and watched them become Bat and Bar Mitzvahs. I have already attended a high school graduation and helped my daughter move into college. The kids call me Mark, but I refer to them as my daughter and son. I am lucky. I know it. And I wouldn't have it any other way. ▲

Mark is 44 and has CF. He is a Director of USACFA and is the Subscription Manager. His contact information is on page 2.

TILLMAN *continued from page 3*

Savara Pharmaceuticals announced it has completed enrollment in its 80-patient randomized, double-blind, placebo-controlled Phase 2 trial of AeroVanc. This study is being carried out at 40 CF centers nationwide and is evaluating the safety and efficacy of either 32 mg or 64 mg doses of AeroVanc inhaled twice daily. Vancomycin is an FDA-approved intravenously administered antibiotic with proven efficacy in the treatment of MRSA infections. AeroVanc is an investigational, proprietary inhaled dry powder form of vancomycin in a capsule-based device designed for convenient self-administration. AeroVanc is currently being developed as a treatment for persistent MRSA lung infection in people with CF. By delivering vancomycin directly to the lungs, higher vancomycin concentrations are achieved at the site of infection, which is expected to lead to improved clinical efficacy. In addition, direct delivery of the drug into the lungs reduces exposure to the drug elsewhere in the body and is thereby expected to reduce the risk of systemic drug-related side effects.

http://outbreaknewstoday.com/savara-completes-enrollment-for-aerovanc-inhaled-mrsa-drug-for-cystic-fibrosis-phase-2-trials-97525/

Unapproved Device Allows CF Patient to Recover for Double Lung Transplant

Hemolung Respiratory Assist System (RAS) is an innovative Pittsburgh-made, dialysis-like alternative or supplement to mechanical ventilation. Hemolung RAS consists of small tubes that connect a fiber-based device to blood vessels. As blood pumps over the fibers, oxygen flows outside to the blood and carbon dioxide returns. Varieties under development consist of small bundles of hollow, permeable fibers. Another difference from previous technologies is that

Continued on page 23

CAREGIVER STORIES

My Mom and Me

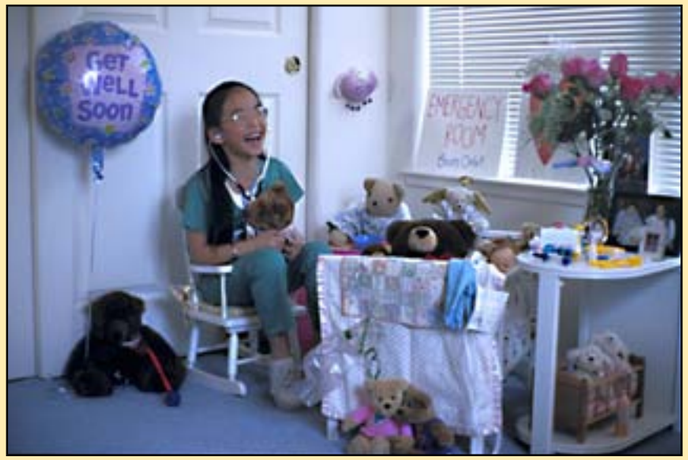


PHOTO BY RAHIM MAU

She helps me a lot on my homework and my journal
She cooks for me
She takes me places.
It makes me happy.
She buys me shoes
She helps me keep my room clean.
She takes care of me.

I brought her meds
I brought her food
I helped take her temperature.
I cared for her.

They took her lungs out and put new ones in
My Dad and I had to wear a mask
In kindergarten we made my Mom a Get Well Soon! poster.
I missed her.

I got to go into the ICU when I was only 5
I always used to ask my Daddy for ice cream from the cafeteria
He always said, "Yes." I said, "Yea!" I had toppings:
Gummy bears, Oreo chips, and chocolate syrup.
I always said, "Thank you!"
My Mom couldn't talk and we had to use sign language
I could understand her more than my Dad
When we visited her on Christmas, I said, "Mommy needs a nap now."
We had to go back the next day to give her the presents.

I had to baby-sit Mommy's little bear, Oats
The bear and I played cards
He slept with me
He helped me brush my teeth, he brushed his.
He ate invisible macaroni.

Isabear gave me Teddy Transplant Bear
I gave him new lungs.
He does not need oxygen anymore.

Mom remembers when I flushed her IV line
I even drew up the saline in the syringe.
I was only 5! Amazing!

Now
She blows on my stomach and my arm
She can yawn! Amazing!
She can go on airplanes! Amazing!
She can breathe again! Amazing!

- M. Mau, 2003

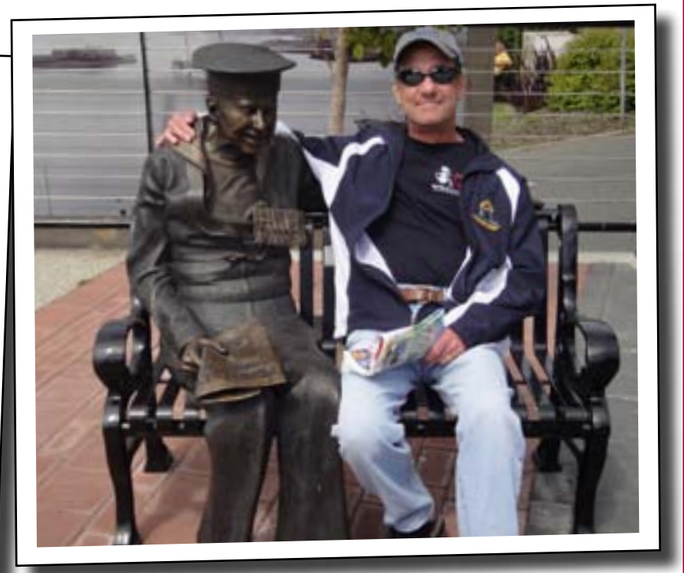
"Through the Looking Glass: Images of Adults with Cystic Fibrosis" and "Caregiver Stories" are projects of Breathing Room, a non-profit organization. Breathing Room hosts these and other projects to facilitate open and candid communication in the CF community, supports the development of a community 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...

BRAD AND LAUREL AVERY.

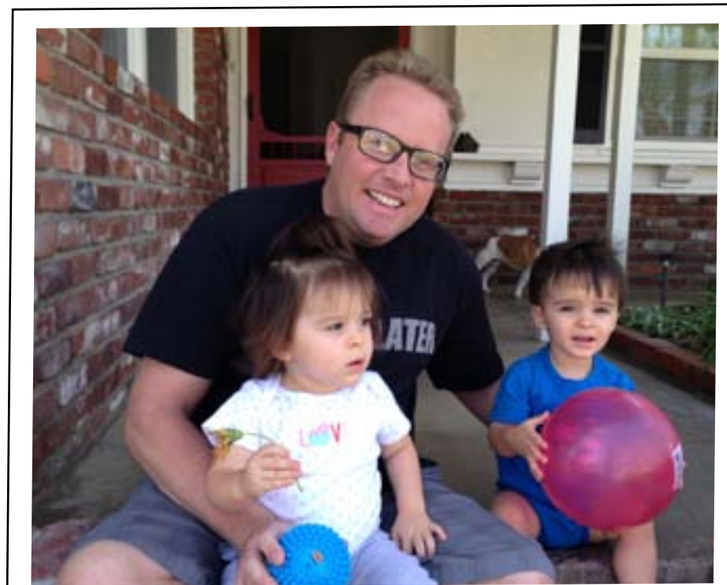
BETH SUFIAN WITH JIM AND ISABELLA PASSAMANO.

JOELLE AND MARK LEVINE.



PAUL FELD WITH A STATUE IN VANCOUVER IN 2013.

CYNTHIA DUNAFON, NEAR THE HORSESHOE MESA AT THE GRAND CANYON, OCTOBER 2014.



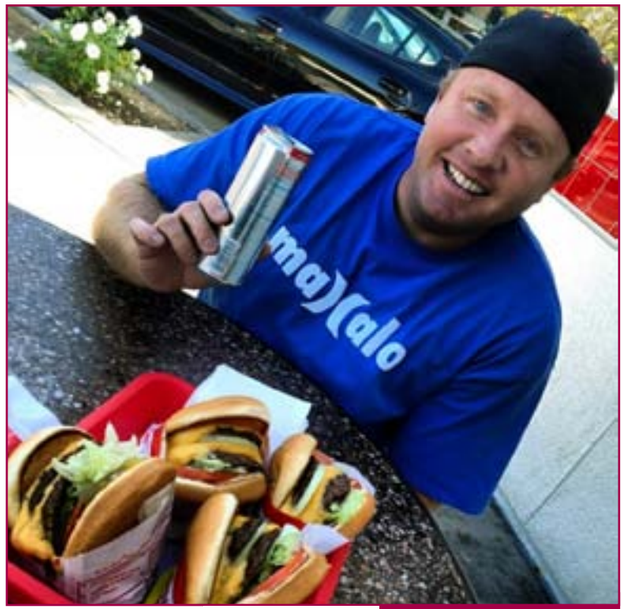
AARON CUNNINGHAM WITH HIS NIECE AND NEPHEW.

JEANIE AND JOHN HANLEY ON THEIR WAY TO ALCATRAZ.

IN THE SPOTLIGHT
With Aaron Cunningham

By Jeanie Hanley and Andrea Eisenman

It's our pleasure to introduce Aaron, who comes to us from the "OC" in California. If you didn't know or remember what it was like to be on the waiting list for a transplant, his story will enlighten you or refresh your memory. So many people have already gone through it, but we've caught him in the middle of his struggles of being listed off and on for lung transplant for more than a decade. As you will read below, Aaron tells it like it is. His experiences are not sugar-coated and represent a window into a life that is in transition. CF clinical trials and transplant centers have undergone so many changes over this time period that his perspective on the differences is also unique. Despite his struggles trying to optimize his health, Aaron's competitive nature has come in handy. He has made whatever changes are needed to fight CF – deciding to "retire" from grad school and his career, changing up exercise routines and switching transplant centers. One of the benefits has been to realize what's really important in life – spending more time with friends and family, especially his niece and nephew, who he cares for nearly daily. I (Jeanie) am a past recipient of his friendship, kindness and generosity when we were both at the same CF center. Aaron arranged to have a goody basket (think chocolate) delivered to me whenever I was hospitalized. He did this for countless others, too. Meet our newest star. Spotlight, please!



AARON CUNNINGHAM

Aaron is 37 years old from Orange County, California.

When were you diagnosed?

I was not diagnosed until my fifth birthday. Up until that point I had had many cases of pneumonia and was severely under-weight (27 pounds at five years of age), despite having an incredible appetite. July 4th weekend was approaching and my regular pediatrician was on vacation. So when my mom called the doctors' exchange, we had to see a new doctor who was covering for the pediatrician. Based on my symptoms, this astute pediatrician suggested a sweat test and the rest is history.

What was your most impressive appetite moment as a child?

At 18 months old I ate my first XL pizza by myself. I would eat and eat until Mom and Dad either got tired of feeding me or I was bored of eating.

How is your appetite now as an adult?

My appetite now is still beyond great. I actually have to watch what I eat so I don't get too heavy. My BMI is 30 on a bad day, so I try to stay around that level for transplant reasons and overall health reasons.

What is your genotype?

Homozygous Delta F508

Which areas does CF affect?

CF has affected many areas of my body: lungs, pancreas (CFRD), liver (cirrhosis), stomach, ulcers and, most recently, some sinus issues. I would say that for me even though many areas of my body are affected, it is my lungs that are the worst.

Do you participate in clinical trials?

I have been participating in clinical trials since late junior high school (over 20 years). It started with Pulmozyme, then TOBI, and after that I have lost track. If a study pertained to me and it was doable for me, I have tried to participate in the trials to hopefully better my life and the lives of other cystic fibrosis patients.

How differently were they conducted then compared to today?

I would say a big difference in clinical trials now vs. 20 years ago is the monetary compensation given to patients. Back when I first started doing clinical trials, the money paid to patients was minimal, if anything. I think the CF community as a whole was mostly concerned about finding out the benefits of the trial for cystic fibrosis patients and less concerned about the monetary compensation. This could also be because years ago CF was more of a pediatric disease; patients weren't living as long so the CF community was more desperate to find drugs and methods of treatment to help the CF community live longer.

How compliant were you as a teenager?

I am compliant and always have been compliant. I have always hated being sick, so I always thought that if I could do something that could help me be less sick, I would do it. People often ask what made me be so compliant. I think it is just the person I am. I have always been super competitive and a rule follower. It started in sports growing up. I wanted to be the best and I wanted to win. I wanted to win fair and square. This attitude has constantly been with me.

Are you still competitive?

When my body was no longer able to compete on the athletic field, I turned my competitiveness to school. I wanted to be the best student with the best grades. While working on my MBA, my health started declining rapidly. I realized that my greatest competition now was with CF. I still want to win. So if that means doing four rounds of breathing treatments, extra vest treatments, and as much exercise as the body can take, depending on how well I am feeling that day, then that is what I do. Doing extra breathing treatments, vest treatments, and getting extra exercise can be tedious and frustrating, but going into the hospital is worse.

Did your friends know you had CF?

I never told friends or people that I had CF when I was growing up because I didn't want special treatment. I was competitive and wanted to compete without people (coaches and teachers) taking it easy on me. I wanted to win fair and square and didn't want to be viewed differently. On the flip side, I found out my parents told coaches and my friends' parents for medical purposes so they'd understand my frequent coughing and large appetite. My buddies and I never discussed it even through college. I wanted to be normal.

What influence did your parents have on your health?

My parents had a huge impact on my health. Growing up I am sure I nearly ate them out of house and home, both before being diagnosed and after. They have always encouraged me to do everything. Sports, music or whatever, it did not matter. When I was young, people were often amazed that I did so much, and many parents would tell my parents that they were unwise to allow so much activity and participation. My parents did not want me growing up in a bubble, or being locked up in the house. They wanted me to live life. They wanted me to do everything that I wanted to do. Their attitude and my attitude has always been: Do your best and let God do the rest.

Do you have siblings? What is your relationship like?

I have one younger sister who does NOT have CF. I think growing up there might have been some tension between us, but now there is none. We don't talk about CF to each other, but she is always concerned and worried about me. She talks with my parents about it. She has three-year-old twins, one boy and one girl whom I consider like my own. They are over at my house all of the time or I am at theirs. I don't have children of my own, but I feel like my niece and nephew are my children. I don't change dirty diapers, though.

When were you listed for transplant?

In March of 2003 my FEV_1 was 22%. I was 24 years old and my health was in a free fall. We did not know if I was going to make it. My lung function was decreasing what seemed like daily. Back then the rules for transplant were different (based on time on the list), so we did not even know if I would be around for a transplant when it was my time for a transplant. We started looking at all of our options – living donor, cadaveric and different transplant centers. It was all very overwhelming.

What did you do?

After some period of time passed, I was able to raise and maintain my FEV_1 to between 48% and 54%. At this level it was not advised that I continue on the transplant list. I agreed with this and was actually given much hope from this improved gain.

Since 2003 the thought of transplant has been a constant roller coaster: being at multiple transplant centers, having multiple CF transplant teams, UNOS rules, changes in treatment and recovery. Everything is constantly changing.

What is your transplant status now?

Two years ago I changed transplant centers. Like anything new, there is a learning curve with a new center, a new team, new UNOS rules, but I am adjusting. My transplant team is great. They seem to be really "on it" and coordinate with my CF Center well. Currently I am not listed for transplant and my FEV_1 is 36%. But I have had the work-up done again and am regu-

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CUNNINGHAM *continued from page 21*

larly followed and seen by my new transplant center at Stanford. Hopefully, with their help, I can continue to put off transplant for many years.

What is your biggest fear of transplant?

To me transplant is such a flip of the coin. It can be great or it can be bad. I have seen CF transplant patients live for years and others not make it out of surgery. It is scary.

How did CF and being listed affect your career?

The possibility of transplant caused me to reevaluate my life. I had to decide on what was important to me. I finally came to the decision that I would stop both pursuing an MBA and my job in finance. I would retire. This was not an easy decision. Looking back I do think it was the right decision to retire. I was working all day long, treatments before and after work, and then, basically, I would go to bed after dinner. Then I would sleep all weekend in an attempt to catch up on sleep. This schedule left me exhausted and frustrated. When I did retire I had much more time to sleep, rest and do extra treatments and extra exercise. Then with all my life changes going on, depression started to rear its ugly head. At first I was in denial, but when people close to me started talking to me about it, they encouraged me to get help.

How did you treat the depression?

I was started on anti-depression medication and have been on it since about the time I was listed for transplant back in March of 2003. Am I proud that I am on it? No. But I think the person that I am when I am not on the depression meds is not me, and that is no way to live. Even being on depression meds I have my ups and downs. In helping myself deal with depression, I have found that exercise is very beneficial. For me it's lifting weights in the gym, walking or swimming. They all seem to help in my fight against depression.

How does your liver cirrhosis affect the transplant decision?

Both my first transplant center and my current center at Stanford follow my cirrhosis of the liver very carefully. Right now my cirrhosis is considered to be biliary cirrhosis, but with future tests scheduled, things could change in terms of my liver and being eligible for transplant.

What is your day like?

Kind of boring, in my opinion.

What about exercise?

Exercise is super important. I don't take inhaled antibiotics so exercise helps me clear out the mucus. I exercise daily. I am in the gym a minimum of five times a week. In addition, I also walk as much as possible and as fast as possible. Due to my low lung function, I am unable to run. In warmer months I try to swim as much as possible. I also jump rope for exercise.

What's your personal life like?

I am single, living and fighting CF full-time, which does not leave a lot of energy or time for dating. I have come to terms with that and I am okay. I am enjoying being an uncle (and dad-like) to my niece and nephew. I live at home and have two dogs. One is a French bulldog and the other is a Scottish terrier.

Are you religious?

Yes, I have a personal relationship with Jesus Christ. Does this help me? Absolutely. And it also gives me hope.

Where do you see yourself in five years?

In all honesty, I don't plan five years out, or ten years out. I take life one day at a time, making the most of each day.

What message do you have for others with CF?

Eat! Give your body the most calories it can to fight this disease.

Live! Don't live in a "bubble," go enjoy life. Do what you can. Chase your dreams.

Be compliant! Do your treatments and then some.

Have faith! ▲

Jeanie Hanley is 52 and is a physician who has CF. She is a Director of USACFA and is the President. Her contact information is on page 2. Andrea Eisenman is 50 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.*

If you would like to be interviewed for "In The Spotlight," please contact either Andrea or Jeanie.

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the new device is worn around the waist, so that patients can move around and strengthen their muscles. Hemolung was recently approved in both Europe and Canada and it is being tested in the U.S.
http://cysticfibrosisnewstoday.com/2014/07/03/unapproved-device-allows-cf-patient-recover-double-lung-transplant/

Parion Sciences Announces $15.6 Million in Grant Support for Pulmonary Research Program

Parion Sciences, a company dedicated to the development of novel treatments for pulmonary and ocular diseases, announced today that the National Institutes of Health (NIH) has awarded up to $15.6 million over five years in grants to the University of North Carolina, Chapel Hill (UNC-CH,) and the University of Colorado, Denver (UCD), to conduct research with mucolytic agents discovered by Parion Sciences and to enable Investigational New Drug (IND) applications for Parion's molecules. Parion Sciences is designing and testing novel mucolytic agents that specifically target mucus structure to facilitate mucus clearance from the lungs. There is a need for agents that clear adherent secretions from the lungs in acute and chronic pulmonary disorders.
http://www.digitaljournal.com/pr/2258446

Birth control implant could ease cystic fibrosis lung exacerbations in female patients

A new study on the effect of female hormones in pulmonary exacerbations in cystic fibrosis patients, entitled "Subcutaneous implant with etonogestrel (Implanon®) for catamenial exacerbations in a patient with cystic fibrosis: a case report" and published in the journal *BMC Pulmonary Medicine* by Dr. Adelaida Lamas, supports previous evidence associating female hormones in the development

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PROTECTING WHAT MATTERS

Planning For A Family When You Have CF

By Mark Manginelli

Elizabeth Stone once said, "Making the decision to have a child is momentous. It is to decide forever to have your heart go walking around outside your body." Bringing another life into this world is exactly that. Planning for a family is a life-changing decision, and having cystic fibrosis makes it that much more challenging.

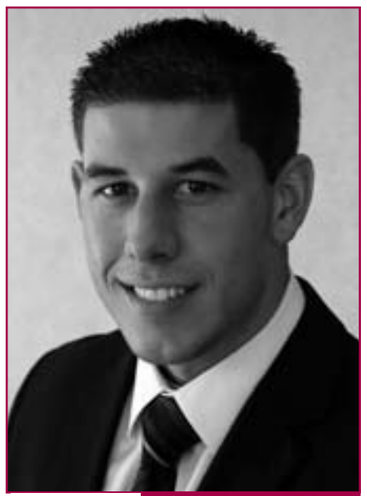
This topic hits very close to home for me as I am only about a year away from beginning my journey of family planning with fertility doctors myself. Although men who have CF can enjoy a normal sex life, they are almost always (about 98% of cases) infertile due to failure of the vas deferens, the tube that carries sperm from the testis to the penis, to develop properly. (www.cfmedicine.com) A sperm analysis can be performed to understand your personal fertility status, and I recommend every male with CF to have this performed.

> *"Planning for a family is a life-changing decision, and having cystic fibrosis makes it that much more challenging."*

Please keep in mind, fertile and sterile are NOT one in the same; I walked around depressed for quite some time when I was misinformed that I was sterile, or not able to produce children of my own. When I was finally ready to conduct my own due diligence, I was pleasantly surprised to read that I can have a child of my own but there are just a few extra steps (and money) in the process to do so.

Planning for a family in and of itself can often be overwhelming. Once you have done the preliminary research that is often required for families with cystic fibrosis, it would be prudent to understand the specific laws in your state surrounding infertility insurance coverage. Unfortunately, the laws surrounding infertility and the insurance coverage to help pay for expensive fertility treatments are not created equal from state to state. Currently, only fifteen states have laws requiring insurance coverage for infertility treatment. These states include: Arkansas, California, Connecticut, Hawaii, Illinois, Louisiana, Maryland, Massachusetts, Montana, New Jersey, New York, Ohio, Rhode Island, Texas and West Virginia. The National Infertility Association (www.resolve.org) recommends that if you live or work in a state that has an infertility coverage law in place, you should:

- Go to its website and click on the state name for a summary of the law, and get the full text from your state legislative website.
- Learn whether your employer plan is fully insured or self-insured. Fully insured plans follow state law. Self-insured plans follow federal law and are exempt from state law.
- Learn if your employer plan is a "greater than 25" plan, "greater than 50" plan etc. In this case, employers with less than a set number of employees do not have to provide coverage.
- Learn if your employer's policy was written in the governed state. Generally, the policy must be written and/or reside in the state that has an infertility coverage law.
- Learn if your employer offers more than one plan. If so, investigate which are fully insured plans in the state with an infertility coverage law.



MARK MANGINELLI

If you happen to live in a state with infertility insurance coverage in place, you're extremely fortunate. If you live in one of the thirty-five other states that do not mandate infertility insurance coverage, there can be a tremendous financial burden carried by many seeking treatment added to the emotional and physical toll exacted by infertility.

Just as a GPS can help you find your way on a trip, it is crucial to have a financial plan to help you stay on course to reach your short-term and long-term financial goals. For the most part, funding these costs are typically short-term financial goals. Long-term goals include appropriate and affordable insurance protection, children's education planning, retirement planning, buying a second home, minimizing credit card debt etc. From a comprehensive-planning perspective, every financial decision you make will undoubtedly have an effect on another element of your plan; for example, how will your cash flow be affected by funding these costs? Do you need to take out another loan or use credit cards to pay for the costs when insurance falls short?

For most people, dealing with their money is an emotional experience and recommended strategies for one family can be drastically different for another, even though they may be dealing with similar situations. In many cases, dealing with a financial professional who can offer you unbiased, objective guidance will give your plan the greatest chance of success now and many years into the future. Utilizing a trusted resource can ensure you take advantage of every possible strategy out there to minimize fees, interest and taxes and help you understand all the consequences of your decisions before they take place. If you do not know a trusted financial professional personally, start by asking family, friends or colleagues for a referral to someone they know, like and trust. When I meet with a family for the first time, the conversations are much more productive from the start when my prospective clients leverage the trust I've built with the person who referred them.

I hope your New Year's resolutions are still going strong and I hope everyone reading this has had a happy, healthy and productive winter! ▲

Mark is 28 and has CF. He lives in Edison, NJ. You may contact him at: mmanginelli@usacfa.org.

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of recurrent infectious pulmonary exacerbations and the deterioration of lung function in a woman with cystic fibrosis. The new findings suggest that hormone-based birth control for women with CF could offer a therapeutic value for avoiding lung function issues. Cystic fibrosis affects both sexes, but there is a sexual dichotomy relative to disease severity, with women having a survival disadvantage and weaker lung function. The origin of this gender difference and susceptibility is not well understood, but in previous studies, female hormones have been implicated in the development of pulmonary exacerbations (PE). This study shows and correlates with former studies that female hormones are crucial players in the development of PE and in the deterioration of lung function in female patients with CF. Notably, the study highlights that hormonal control through contraceptive methods may be considered as a possible treatment for this pathological condition.

http://tinyurl.com/kk68ycp

New cystic fibrosis drug treatment may be 'potential game-changer'

Researchers found that Cysteamine, given alongside a second drug, epigallocatechin gallate (EGCG), reduced inflammation in patients' airways and also dramatically reduced the levels of salt in their sweat. The researchers are now hoping to set up a large-scale trial to prove the drug combination's effectiveness across an international CF population, which could lead to a completely new approach to therapy for the commonest form of CF.
http://news.stv.tv/tayside/299247-dundee-university-part-of-study-in-cystic-fibrosis-treatment/

PulmoFlow's nebulized drug and device combination gets FDA approval for cystic fibrosis

The FDA granted final approval of PulmoFlow, Inc.'s New Drug Application for Kitabis Pak. The drug is a co-packaging of tobramycin inhalation solution and the PARI LC PLUS® Reusable Nebulizer, which is the first combination of its kind approved and indicated for the treatment of respiratory infections caused by Pseudomonas aeruginosa in adult and pediatric patients with cystic fibrosis (CF). Kitabis Pak sets a new standard for nebulized drugs similar to asthma and COPD inhalers where the drug and device are prescribed and dispensed together. The price of Kitabis Pak will be similar to the price of generic tobramycin drug alone.
http://www.news-medical.net/news/20141203/PulmoFlows-nebulized-drug-and-device-combination-gets-FDA-approval-for-cystic-fibrosis.aspx

AND

http://cysticfibrosisnewstoday.com/2014/12/04/tobramycin-nebulizer-kitabis-pak-fda-approved-for-cystic-fibrosis/

FYI

Early colon screening of adult patients with cystic fibrosis reveals high inci-

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PARENTING

CF Dad – An IVF Story

By Anonymous

I'm a 42-year-old husband and father of two. I was diagnosed with cystic fibrosis within three months of my birth, during a hospitalization for pneumonia and very poor weight gain. The early label "failure to thrive" along with family history of CF (my two older cousins) gave cause for a sweat test that confirmed the diagnosis of the disease.

Staying on top of my treatments and managing my CF became second nature as my parents transitioned me from being told each time, to occasional reminders, to taking full responsibility. Growing up as a "kid with CF" in the '70s and '80s had its own share of challenges. There were half as many drugs for CF as today. Most of my days consisted of just taking my albuterol, pancreatic enzymes and some manual chest percussion. Oral and IV antibiotics ruled the '70s (shout out to ole reliable, Keflex), which progressed to my use of inhaled tobramycin by the late '80s.

I would have to say my greatest obstacle with CF as a child was the looming dark shadow on my indefinite future. Sure, none of us on this planet have a clue what to expect from day to day, but a child growing up with CF in those days had to come to terms with all of the CF literature that drilled into my mind how lucky I would be to reach age 20; and forget about getting a college degree, marriage, having a family and a career.

Even harder to digest was living through childhood watching all of those dismal predictions play out with my two older cousins and so many other kids from my CF clinic. Luckily, my parents and pediatric CF doctor encouraged me to live as normal a life as possible and find ways to work around my cystic fibrosis in order to pursue my life's goals and dreams. And pursue I did.

Upon completion of public school through 12th grade, I moved on to attend college and completed my Bachelor of Fine Art. My degree allowed me to pursue a career in education, where I worked as a certified K-12 Fine Art Teacher for multiple elementary and middle schools.

> *"Prepared to take on whatever lies ahead, my wife and I started our walk together down the path of parenthood."*

I met the love of my life during my college days and became the luckiest man alive when she agreed to live out our days together in matrimony. I was on top of the world. I reached adulthood, earned a college degree, started a career and got married. What more could I ask for?

The first answer to that question is simple—more time. The second part of that question terrified me—children. I'm a teacher, so it wasn't a fear of being around children. It was the idea of taking on parenthood and knowingly exposing my kid to the ugly faces of CF as I lived through each progression of the disease. It was a heavy decision to weigh as my wife and I planned our future family together.

My wife felt she was strong enough to handle the possibility of raising kids in the midst of my CF. I came to peace with the looming possibility of not being around when my children grow into adults. Prepared to take on whatever lies ahead, my wife and I started our walk together down the path of parenthood. We spent the first two years trying for children without the help of any doctors. Given that my wife didn't have cystic fibrosis, we both knew my CF made the odds I could conceive a child without assistance from modern medicine very unlikely. Even still, we had to try on our own.

I don't recall when exactly, but somewhere towards the end of the first year of trying, my wife and I decided to step it up a notch and started targeting intercourse during her most fertile time of her menstrual cycles. That didn't work either.

By year two, we had to face the music and agree to see an infertility specialist. We set up the orientation appointment, psychologist assessment and follow-up. The hang-up to the process turned out to be the hefty price tag that came with infertility.

We were all too familiar with the financial burden of infertility. At that time in our lives, we already had friends who had racked up, basically, a second home mortgage trying to get pregnant through infertility treatments. My wife and I were on the same page in that we both agreed to set a financial cap and stick to it, no matter what. It was important for us to set that cap before we started treatments, in order for us to not let emotion rule us and drag us into financial ruin as it had with our friends.

So there we were—we passed all of the assessments and physical exams, had an estimated cost of each procedure and set a financial cap. We were green-to-go except for one thing—the green. We didn't have the available cash to pick up the tab, and our health insurance was little to no help. We weren't going to let that get in our way at this point in the game.

> *"We already had friends who had racked up, basically, a second home mortgage trying to get pregnant through infertility treatments."*

It took another year before we could save up enough money to get started on the infertility treatments/procedure. Oh what a happy day it was when my wife and I walked into that doctor's office ready to write a check and begin. Little did we know, that day was the happiest moment we would have in that office for the next 18 months.

The first three attempts did not take. I worked as much as I could squeeze into a day in order to keep trying. The emotional toll of the failed attempts and the physical toll of working extra jobs to help fund the procedures was breaking me down. The emotional roller coasters that came with each procedure took a huge toll on my wife as well. On top of all of that, our predetermined cap meant we would stop at the fifth attempt; and I can't begin to put into words how exponentially frustrating each failed attempt was to us.

Our luck changed on the fourth attempt when the doctor called us into his office to personally congratulate us on our pregnancy. Soon after, we had our first sonogram. We both wept with joy upon the first images of our baby. The second sonogram was considered routine, so I chose to save one of my personal days and let my wife go to the appointment alone. That's when things got really interesting.

I recall my wife calling me from the doctor's office with the kind of shaky voice that evokes tears rolling down her face. My first instinct was something terrible was revealed and to brace myself. With that sinking feeling in the pit of my stomach, I prepared for the worst, only to be blindsided by the best of news—we were pregnant with twins!

Upon review of the angles of both sonograms, the doctor determined our little bundle of joy had split into two bundles of joy. The doctor asked my wife if twins ran on her mother's side of the family. Well, it turns out they do. Twins were prevalent on my wife's maternal side but skipped the last two generations. Her family didn't warn us of the possibility of having twins because nearly 90 years had passed since the last set of twins. O the laughs we had as elder family members began recalling all of the stories of twins that popped up along my wife's family history.

My wife's pregnancy went well, considering all the difficulties of carrying multiples. My twin girls were born premature, as expected, and spent the first two weeks of their lives in the hospital. Though those first weeks were challenging, I drew hope from the joy and thankfulness my little girls didn't have CF. That little detail was a big deal to me. So much so, I insisted my wife be tested as a possible carrier of the CF gene before we considered planning our family together.

I was willing to take on whatever came with parenthood. But at that time in my life, I felt I wasn't strong enough to cope with raising a child with CF. I'm older and wiser now and no longer see raising a child with CF as an Achilles heel that would bring me to my knees. I've learned people and their views must be allowed to change, including myself, and have forgiven myself for thinking that way.

Adapting to change is the name of the game when it comes to raising children. That proves even more difficult when trying to stick with my personal regimen of CF treatments and therapies. I found it very easy to lose myself on the back burner as I prioritized the needs of a child completely dependent on me for her survival.

Between raising my kids and trying to keep a full-time job, my next highest priorities were eating and sleeping just enough to make it through the next day. Given, each parenting experience is unique. Mine included trying to survive the first 16 months of sleep deprivation. My wife and I took shifts; and though she shouldered most of the evening burden, I found the cry of a baby to be most effective at pulling me out of the deepest of sleep.

Basically, I was a sleep-deprived zombie those first 16 months as I mulled through my day, incapable of remembering much of anything more than my kids' feeding schedule. My kids were relatively healthy aside from a few lingering complications associated with being born premature. Even still, it seemed like every spare moment I had was used to go to the store for more baby food and diapers or take one or both kids to the pedia-

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MEET THE NEW DIRECTORS

Meet Laurel Avery–Director

It is a pleasure to meet all of the CF *Roundtable* readers. My name is Laurel W. Avery. I am excited and honored to be a newly appointed Director of USACFA.

I was diagnosed at three months of age and am 38 years old, now. I was raised in Plattsburgh, NY, with my younger brother, Parker, who also was born with CF. I attended Union College in Schenectady, NY, graduating with a BA in Political Science. I have been involved in fundraising for cystic fibrosis since college. Currently, with the support of my local community, we host a Cystic Fibrosis Foundation Great Strides event.

I reside in Northern Virginia with my husband of 11 years and two wonderful dogs. I am happily married to my best friend whom I have known since the fifth grade. He is my soul mate.

I have spent the last 10 years of my life as the head of Sales/Business Development for companies responsible for conducting clinical trials for pharmaceutical companies. Though I recently retired, I was lucky enough to meet some of the most influential scientists working in the field of CF. In my retirement, I enjoy cooking and spending as much time as I can with my family and friends.


LAUREL AVERY

With the recent passing of my brother, Parker, my involvement with USACFA is very meaningful to me. Parker always wanted me to get more involved with the CF community. He would be thrilled that I am participating in an organization dedicated to helping others with CF.

Meet Klyn Elsbury–Director

Klyn Elsbury lives in San Diego, California, where she is a part-time licensed Zumba dance instructor for several boutique gyms. Diagnosed within 24 hours of being born, she has 26 years experience in conquering cystic fibrosis.

This year, she took a step back from her high-pressure biotech and pharmaceutical recruitment career to focus on improving her health, as well as educating/inspiring others to reach for what is actually important in life. Recently she was elected Chairwoman of Board Development for the Cystic Fibrosis Lifestyle Foundation. She was the top fundraiser for San Diego's Finest campaign. She was elected to be a member of CFF Young Professionals.


KLYN ELSBURY

She isn't engaged or married and does not have kids, but with as much food as she eats, you'd think she has a family of four. When she isn't Zumbaing, volunteering or making jokes—she's networking with new people and enjoying caramel iced coffee from Starbucks on the beach (tough life). As a positive and comedic socialite, Klyn brings the ability to further CF Roundtable's mission of offering hope, support and news in the world of cystic fibrosis.

Meet Chris Kvam–Director

I was diagnosed with CF in 1984 at the age of four. I grew up with CF, and have benefited from every significant advance in CF care over the last 30 years. I do not define myself by my CF diagnosis. I am a spouse, an Assistant District Attorney and an athlete. In addition to a law degree, I also have earned a Masters of Public Policy.

I care deeply about finding better ways to help people with CF cope with the many challenges that accompany living with progressive chronic illness and the massive treatment burden that comes with CF. Adherence, quality of life and mental health issues associated with CF interest me as much as current science. I motivate adherence to my CF regimen by setting goals that require adherence.


CHRIS KVAM

I ran competitively through college, and continue to use exercise to motivate adherence. I have run a marathon, have completed a half ironman, have ridden my bike thousands of miles and am an avid skier.

Living fully with CF requires coping skills and an appreciation of the person with CF as a whole person, not as a patient defined by a condition. I look forward to being a part of this important publication.

Pay It Forward

Again, our readers continue to amaze us. Our first fundraising campaign continues on – beyond our expectations! We are overwhelmed by your generosity and support of our efforts to make *CF Roundtable* available for free. We thank you for your continuing endorsement of our endeavor.

Below is a list of those who continue to "pay it forward":

Rebecca Eller
Susan Le Boeuf
Adi Loebl (In honor of Andrea Eisenman's 50th birthday & 15th transplant anniversary)
James Nash
Reiner and Hatsuko Stenzel (In memory of Anabel Mariko Stenzel)
The Sufian Family (In honor of Andrea Eisenman's 50th birthday & 15th transplant anniversary)
Laura and Lew Tillman (In honor of Andrea Eisenman's 50th birthday & 15th transplant anniversary)

ANONYMOUS *continued from page 27*

trician (thank goodness for pediatrician offices open on Saturdays).

Making time for myself to do every breathing treatment—well, I'm first to admit how disastrous that turned out. And forget about going back to count how many times I fell asleep in the middle of doing a breathing treatment and let the nebulizer fall from my mouth to floor, along with the liquid contents that rival the commercial value of pure gold. To further that bit of twisted comedy, even to this day (though less often than during those infant/toddler years), I continue to spill my medicine all over the floor when I fall asleep during breathing treatments.

It's safe to say balancing parenthood with my regimen of CF therapies remains no easy task. Now that my kids are older and their schedules are more predictable, I'm able to plan around their routines and do more of my CF treatments and therapies. But life has a humorous way of keeping us on our toes. And just about the time I find a groove and get better at staying on track with my CF regimen, consuming enough calories, sleeping better and exercising more often, life will throw me a curve ball and change things up. Don't get me wrong, that's okay. Adapting to change is paramount to staying happy and healthy. Parenthood is merely a multiplier of adapting to more change. By day's end, when the kiddies nestle in for bed, I inevitably reflect in total amazement and wonder, "How did I pull off that day?!?!?"▲

The author has requested to remain anonymous.

Voices from the Roundtable

Winter Hospital Spirits

By Beth Sufian

Winter is here and that means many people with CF will get sick and go into the hospital for short and sometimes long stays. In the 1990s I had many hospital stays. My record was set in 1996 at 92 days. I was so sick even the nurses questioned whether I was going to make it. But even during the darkest hospital days, I found ways to stay hopeful for a brighter future.

Someone recently asked me how I kept my spirits up during long hospital stays. I have tried to write about things that helped me. This is the first time I have ever written an article about a hospital stay, so it is new territory for me. Two of my best friends, Isabel Stenzel Byrnes and the late Ana Stenzel, have always encouraged me to write about my experiences as a way to find peace in life. So I decided to try it.

I think hospital stays are easier now thanks to smart phones and the Internet, but my longest hospital stay was over 18 years ago. Visits from my husband, family, friends, wonderful nurses and hospital staff helped brighten the days. I also kept busy answering legal questions. After a few weeks, word got out around the hospital that a lawyer who helped children with chronic illness was in the room at the end of the hall on 4 South. Doctors, hospital staff and parents started to come to my room with legal questions. There were so many "legal visitors" that my doctor said I had to establish office hours. The teenager/artist across the hall made a sign with bold colors that announced my daily office hours.

My spirits were also lifted by the children and teenagers occupying the 4 South rooms who showed me the meaning of courage each and every day I was in the hospital. All of them had been through long hospital stays and had helpful advice. Some children had parents who could not visit very often due to work schedules or other reasons. I spent time helping those children, whenever I had the strength.

I am sure some parents of young children reading this article are wondering how in the world I was talking and interacting with children with CF on a hospital floor. It was 1996 and just at the beginning of the medical awareness of cross-infection issues, at least at my hospital. There were no rules about interacting with each other.

> "The children with whom I became friends during the longest hospital stay helped raise my spirits in 1996 and have done so again in 2014."

I mainly visited with my CF pals in the "teen room." I was not a teen, but at the time adults with CF were still seen in pediatric centers and admitted to pediatric hospitals. I was allowed in the teen room even though I was 31 years old. At the time I weighed 88 pounds and was 5'1" so I was actually mistaken for a teenager many times during hospital stays.

When I was having a good day, I planned outings with the kids to the cafeteria for popsicles, French fries or candy bars. It took some planning as many of us were on continuous IV fluid when not receiving IV antibiotics. We needed to be able to push our IV poles and push the children on oxygen, who needed a wheelchair to make the trip downstairs. We sang songs and laughed all the way there and back. Definitely something that lifted my spirits.

Halfway through my hospital stay my spirits were low. My Pseudomonas was not responding to the IV antibiotics and each day it became harder to breathe. My spirits were raised when I was called on to plan a birthday party in two hours. The nurses found out a 9-year-old child's parents would not be coming to the hospital that day to celebrate his birthday. The nurses wondered if I could help as they were short staffed and could not leave the floor to buy the things needed for a makeshift party. I gathered all my energy and raced (walked carefully with my IV pole) to the hospital gift shop. I bought balloons (yes, there was a time when they allowed balloons in the hospital) and presents for the birthday boy. Then on to the cafeteria to buy cookies, ice cream and the last slice of cake left over from the lunch rush for the birthday boy.

At a time when it seemed unlikely I would live long enough to be a mother, it was a chance to be cast in a mother-like role. If I would not be able to plan a birthday party for a child in the future, I could make this party a joyous celebration for a little boy who had very little and was near the end of his life. When I have been faced with difficult work days in the past six months, I have remembered that party. The children with whom I became friends during the longest hospital stay helped raise my spirits in 1996 and did so again in 2014.

The 4 South Group was intrigued by my job as an attorney who helped children and young adults with CF. Some teenagers arrived during office hours and told me of trouble with their schools. The school administrators were insisting they must take exams in the hospital and complete major projects while hospitalized. I contacted their school principals to explain that under federal law the students should be given a modification of the date to turn in the exams or projects. I negotiated an extension of time to finish the work or a delayed exam date for many of the teenagers on 4 South (and some on 4 North too).

The principals asked how I had consulted with my clients so quickly about their offer. I said, "Well, they are very close to where I am working." Which was true. Little did they know I meant I was working out of a hospital room and my clients were only steps away in their own hospital rooms. The stress the teens were feeling about schoolwork disappeared. The students could focus on their health and fighting their serious pulmonary infections. My spirits were raised.

One night the usual group of around 10 was in the teen room talking. The age range was between 9 and 17 years of age. Some of the younger children asked when I thought there would be better treatments to help us. No one thought a cure would arrive in time for them, but all thought it would be great if new treatments came soon. Half the children had very low lung function and the other half were finding it difficult to stay out of the hospital for more than a few months at a time, due to frequent lung infections.

In 1996 treatment options were very limited. It was the early days of transplant. In 1996 I attended 10 funerals for children I knew with CF. As we begin 2015 with so many treatment options available, younger members of the CF community often tell me it is hard for them to believe there was a time when there was not much that could be done to fight CF.

The clock struck 9 PM and it was time for us to return to our rooms and be hooked up for our night-time IV antibiotic doses. One teenager said, "I want you to promise that you will make sure that all people with CF, even those who are poor, have access to new medicines." "Yes, yes you must promise," the others said.

None of the children were sure if they would be alive to benefit from future advancement in treatments for CF, but all of those present were worried that children with CF who were poor would not have access to any future new treatments. I promised I would continue to do what I could to make sure that everyone had access to the medicine they needed to fight CF. As we walked out of the teen room, every face had a big smile.

On day 78 of my longest hospital stay, one of my physicians, Dr. John Jacoby, suggested I add a third IV to my treatment and I finally started to get better. Dr. Jacoby was a physician who also had CF. I visited him in New York every six months for four years, in addition to seeing my CF physician in Houston.

Dr. Jacoby was a brilliant physician. His dedication to serving others was never-ending and those who knew him marveled at his commitment to helping people with CF. He provided me with excellent medical care and an understanding of CF that could come only from a person who shared the disease. More importantly, he gave me the courage to continue to fight CF, even when I thought I could not fight anymore. He was my hero. He raised my spirits by figuring out how to make me better and in doing so he saved my life.

Thanks to medicines like Pulmozyme and later Cayston, my hospital stays decreased. I enjoyed a healthy 2014 with no hospital stays at all. My terrific CF Center team, my fantastic home team—husband, daughter, mother, father, sisters, brother-in-law, nephew and, of course, my incredible friends—have provided the support, love and inspiration I have needed in the past year to stay healthy and to keep that promise I made 18 years ago.

My column in the Autumn 2014 issue discussed the work my law partner and I have been doing for the past six months. We worked 1,800 hours for free on the Arkansas federal civil rights lawsuit we brought to obtain coverage for Kalydeco for three girls who had been denied coverage for the drug by Arkansas Medicaid. As the Wall Street Journal reported, Vertex Pharmaceuticals, the company that makes Kalydeco, also failed to provide the drug to the girls while they appealed the denial of coverage by Medicaid.

As during my longest hospital stay, there were dark days during our work on the Arkansas case. As we worked with Arkansas Medicaid to provide coverage of the drug to the girls, we just needed provision of the drug for a short time. The girls' physicians asked Vertex to provide the drug until we could obtain Medicaid coverage. Vertex never provided the drug to the girls, even though there is no law that prevents the provision of on-label drug to a patient.

These were dark days. Darker than any of the days I spent in the hospital. There were people who, with one stroke of a pen, could stop the suffering of a child with CF but chose

Continued on page 33

Mailbox

I am the mother of one daughter with CF and one daughter who is a CF carrier. I am so thankful for your informative blogs and newsletters. It keeps us in the know and I am encouraged by the milestones of birthdays. I am praying that one day my daughter gets to see her name up there with birthdays in the 50s as well!

Thank you. What you do makes a difference.

Sincerely,
Tina Naftzger
Geneva, OH

I have a daughter with CF who received bilateral lung transplants one year ago and I just wanted to let you and all the staff/contributors at *CF Roundtable* know how extraordinarily helpful and informative the newsletter is. I have been a subscriber for years and look forward to every issue. It really is a wonderful source of support and very much appreciated.

Thanks again,
Lucie Wiseman
San Diego, CA

[This donation is] in memory of our beloved daughter Anabel [Stenzel] who fought with her CF, transplants, and cancer as hard as she could. We are so grateful for your friendship and support.

Reiner & Hatsuko Stenzel
Pacific Palisades, CA

Thanks for the wonderful Autumn 2014 edition of *CF Roundtable*. The articles on new airway clearance therapies and the potential for stem-cell treatment were really interesting and provide significant help and hope.

However, it was the focus topic, "Dealing With The Death Of A Loved One With CF" that I found enthralling. All the articles were quite inspirational in a variety of ways, but for me it was Isabel Stenzel Byrnes who hit the nail on the head. I don't have CF and I'm not a twin, but I felt an amazing affinity with Isabel. I was married to my wife, Kathy, for 50 years before she died, and I guess that's as close to being a twin as you can get. I experience most of what Isabel describes, and it was exciting and uplifting to realize that someone had gone through exactly the same feelings and thought process I had. She provides some wonderful and hopeful guidance like, "Grief reminds us that we are spiritual beings having a human experience" or "we survivors have a responsibility to engage in life while carrying around a collective sorrow for our CF community." Isabel's thoughts are particularly comforting to me as my wife's brother is now dealing with apparent end-stage CF.

Thank you so much for this focus topic. I think it's of great value both to CF patients and to caregivers and loved ones.

Richard Harris
Bowie, MD

Thank you for a very informative and wonderful newsletter. I really enjoy reading it from cover to cover. I have CF and on October 1, 2014, I received bilateral lung transplants at Barnes Jewish Hospital in St. Louis, MO. I am doing well, so far, except for the pain – not only my incisions – but my back hurts worse than the incisions. (I have severe scoliosis.) I was on the list for one year and eight months and was beginning to think it was never going to happen. Keep up the good work!

God bless you all,
Johanna Libbert
Richland, IN

SUFIAN *continued from page 5*

may be limited time periods when a person can switch from certain Medicare Advantage Plans back to original Medicare.

A Medicare supplement is often a good choice for people with CF who need a supplemental policy that will pay the Medicare Part B co-pays and deductible. However, many states do not require insurance companies that sell Medicare supplement plans to sell policies to people on Medicare who are under age 65. So some people with CF will find they are not able to purchase a Medicare Supplement plan or a Medigap Policy.

A person can always ask a provider or hospital to waive the 20 percent Part B co-pay or ask for a waiver of the Part A hospital deductible. There is no legal duty to waive the co-pay or deductible, but most providers will waive such co-pays or deductibles if the patient provides evidence he cannot pay the co-pay or deductible. If a person has a private insurance policy or has Medicaid, then the Part B co-pays and Part A hospital deductible should be paid by the other coverage. ▲

Beth is 49 and has CF. She is an attorney who specializes in disability law and she is a Director of USACFA. Her contact information is on page 2. You may contact her with your legal questions about CF-related issues.

SUFIAN *continued from page 31*

to do nothing.

On the darkest of days I remembered my 1996 hospital stay and the promise I had made to my 4 South friends. I also thought of so many others with CF who had remained hopeful during extremely difficult times. I thought of a new friend, a little girl who does not have CF but whose strength in the face of complex medical issues is remarkable. She lives each day to its fullest and never gives up. My spirits were raised and I found the strength I needed to continue fighting for the girls.

As you may have read in the last issue, my law partner, James Passamano, and I obtained coverage for Kalydeco from Arkansas Medicaid for our clients. By the time this article is published we will have saved our four clients in Arkansas (a fourth girl became our client after the case was filed). The resolution of the case will also provide a framework for all other Medicaid agencies to keep providing coverage for Kalydeco to people with CF across the United States. We found good people in Arkansas and we are thankful for their commitment to helping people with CF.

I think my 4 South friends must be smiling in heaven. The new advances in CF treatment came too late for them, but when I go to sleep each night I know I did my best to keep my promise to them. I will continue to make sure that those who are poor have the same access to life-saving treatment as those who are rich. I will continue to make sure that everyone with CF has a chance at a brighter future. EVERYONE. ▲

Beth is 49 and has CF. She is an attorney who specializes in disability law and she is a Director of USACFA. Her contact information is on page 2.

TILLMAN *continued from page 25*

dence of adenomatous colon polyps. Billings JL, Dunitz JM, McAllister S, Herzog T, Bobr A, Khoruts A. J Clin Gastroenterol. 2014 Oct;48(9):e85-8.

The primary aim of this study was to estimate the incidence of adenomatous colon polyps in patients with cystic fibrosis (CF) during systematic screening by colonoscopy. CF has features of a hereditary colon cancer syndrome. Increasing life expectancy of CF patients suggests that earlier colon screening in this population may be warranted.
http://tinyurl.com/lsujqc2

Pneumothorax in cystic fibrosis. Kioumis IP, Zarogoulidis K, Huang H, Li Q, Dryllis G, Pitsiou G, Machairiotis N, Katsikogiannis N, Papaiwannou A, Lampaki S, Porpodis K, Zaric B, Branislav P, Mpoukovinas I, Lazaridis G, Zarogoulidis P. **J Thorac Dis. 2014 Oct;6(Suppl 4):S480-7**

Pneumothorax is recognized as a common and life-threatening complication in cystic fibrosis (CF) patients. Structural impairment and altered airflow dynamics in the lungs of CF patients are considered as the main predisposing factors, but also inhaled medications and non-invasive positive pressure ventilation (NIPPV) could increase the risk of pneumothorax. Management of spontaneous pneumothorax includes intercostal tube drainage, video-assisted thoracoscopic surgery (VATS), and medical or surgical pleurodesis. Pneumothorax increases both short- and long-term morbidity and mortality in CF patients and causes significant deterioration of their quality of life.
http://tinyurl.com/lu5bw5u

Diagnosis and treatment of endocrine comorbidities in patients with cystic fibrosis. Siwamogsatham O1, Alvarez JA, Tangpricha V. Curr Opin Endocrinol Diabetes Obes. 2014 Oct;21(5):422-9

As life expectancy in cystic fibrosis has continuously improved, endocrine complications have become more apparent. The common endocrine complications include cystic fibrosis related diabetes, cystic fibrosis related bone disease, vitamin D deficiency and poor growth and pubertal development. Thyroid and adrenal disorders have also been reported, although the prevalence appears to be less common. This review summarizes the updated screening and management of endocrine diseases in the cystic fibrosis population.
http://tinyurl.com/oqqouv5

Protein is an important but undervalued macronutrient in the nutritional care of patients with cystic fibrosis. Engelen MP1, Com G, Deutz NE. Curr Opin Clin Nutr Metab Care. 2014 Nov;17(6):515-20

Body composition assessment and achieving protein balance in the routine care in CF is important to prevent muscle loss and to further improve the clinical and overall outcome. New approaches are needed to optimize the interaction between high essential amino-acid-rich protein intake and pancreatic enzyme regimen in CF. The optimal level of protein intake needs to be assessed in clinically stable CF patients as well as in those recovering from an acute exacerbation.
http://tinyurl.com/pucvqwa ▲

Laura is 67 and has CF. She is a former Director of USACFA. She and her husband, Lew, live in Northville, MI.

PAY IT FORWARD BY DONATING TO USACFA, Inc.

As the new year begins, what better way to "Pay It Forward" than by making a tax-deductible donation to USACFA, the publisher of *CF Roundtable*? You might be wondering why you should make a donation. Please read our mission and why any kind of donation is important to keeping *CF Roundtable* alive.

Before *CF Roundtable*, there were no means of communication about how adults with cystic fibrosis lived. We never had magazine subscriptions or newsletters geared toward adults and how they lived their lives with CF. We never read about adults beating the odds, inspirational stories on how to live with cystic fibrosis or successful lung transplants.

This is YOUR newsletter and because of your donations, YOU have made this newsletter possible. We can now read others' stories, relate to them and know we are not alone in our struggle. With your help by making any kind of donation, we can continue our mission to provide you with inspirational stories, articles and interviews, as well as new research and events regarding cystic fibrosis.

All work is done by volunteers and 100 percent of every donation goes into the production of the *CF Roundtable* newsletter and supporting services encompassing USACFA.

For the new year, would you like to make a special donation in honor or in memory of someone who has died? What about making a donation in celebration of a special milestone such as a transplant anniversary, birth of a child, wedding or a birthday? This is a great way to honor and remember someone, and there is no greater reward than celebrating YOU and YOUR accomplishments. We will publish all donations in our next newsletter.

USACFA, Inc. proudly produces *CF Roundtable,* a newsletter for adults who have cystic fibrosis.
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CF Roundtable

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