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.

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

"For people with osteopenia, like me, the goal is to prevent one’s condition from progressing to osteoporosis."
Information From The Internet...

Compiled by Laura Tillman

PRESS RELEASES

Lynxov Designated Orphan Drug for Cystic Fibrosis

Novobiotics announced that the FDA has granted Orphan Drug designation to Lynxov (NM001) for the treatment of cystic fibrosis (CF). Lynxov has a dual antibacterial-mucociliary mode of action that aggressively tackles both of the major clinical features responsible for progressive lung disease in cystic fibrosis. Lynxov 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. Lynxov is being developed as an oral tablet for acute exacerbations and as an inhaled dry powder for chronic use and maintenance. Lynxov is intended for use alongside existing cystic fibrosis treatments and potentiates their antimicrobial effects. A Phase 2a clinical trial for the oral form of Lynxov is already under way. Clinical development of the inhaled form is also anticipated to get under way in 2015. http://www.empr.com/lynxov-designated-orphan-drug-for-cystic-fibrosis/article/371729/

Durham’s Parson receives SSM 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 and Parion will test its experimental drug, called P-1037, in patients with CF. Parion scientists designed P-1037—a spherical cationic polymer—to block sulfur 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.bjournals.com/

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

Continued on page 16

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 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 to contact us, so it is best to contact us directly. 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: 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: 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?

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 Medicare is typically under the age of 65 and is eligible for Medicare because the person is receiving Social Security Disability Insurance benefits.

Q: If I receive Social Security Disability benefits and I have a certain amount of work activity that makes me unable to work full-time, 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.

A: Many people with SSI and Medicaid benefits.

Q: I receive Medicare because the person is under the age of 65 and is eligible for Medicare because the person is receiving Social Security Disability Insurance benefits.

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 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 Insurance benefits.

The monthly amount of SSI benefits a person receives each month and the deductions from benefits that will be made if a person on SSI receives income from work activity.

Q: If I receive Medicare and Medicaid benefits, I understand that Social Security seems to have increased the number of eligible people who receive Medicare 29 full months after his date of disability, which is the date he became incapable of substantial gainful activity. 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.

Continued on page 32
We all die. The goal isn’t to live forever; the goal is to create something that will.—Chuck Palahniuk, Daryn "With your lung function, I strongly advise against getting pregnant." Those were the words my doctor said to me three weeks after I stopped coughing. 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 they 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 breathing. I have four-legged children. I’m just happy to be alive.

"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 want 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 our page. Though 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 Peneucl has shown that writing down difficult thoughts and feelings, can change heart rate, blood pressure and cortisol (stress hormones) levels—practically better. He has found writers who only write negative memories—called ruminations—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 see from one’s own perspective and then reflect on others’ points of view, also seems to be a sign of healing writing."

"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 want 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 our page. Though we are becoming the heroes and heroines of our own stories."
What a year this has been. My health has been good. So that makes it a very good year, in my book. I had cataactcattactcatts removed from both eyes and now I can see without glasses—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.

Recently, as Paul and I talked about our anniversary, we realized that we had 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 work with no color. We 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 with CF.

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 whole trip home. She then transformed 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 give 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. 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.

We will go back to paper. The CF Roundtable is a forum for adults who have CF. More about that, later.

In each issue, on page three, we list suggestions for articles that we would 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 that. Changes and people may write about any CF-related topic that we are interested in. We hope to have photos and text published in full color. We love to share photos with our readers.

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S
ince 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 related, so it works for me.

Stress is not a lighthouse hearted topic, but given the recent findings of 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-popping. Specifically, there are elevated signs of depression in 10% of adolescents with CF, 19% of adults with CF, 37% of caregivers, 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 too to three times greater than in the 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 just stop 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—pure intended. Chronic stress wears on the body, physically and mentally. It always is there; ready to run your day if you let it. Hence the findings of the TIDES study.

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 mediations 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 overall 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 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 realization that living a healthy meditation and 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 spurtin culture results, losing friends and another sibling to CF, losing my parents, and generally weathering the storms of slow decline. I won’t say those things have been easy, but becoming familiar with that place beyond my mind and body has helped.

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 ever sell the idea as a Buddhist theory—this was a hospital, after all. Somehow, he had to secularize what he did every day. He needed to create something that would benefit sick people 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 mindfull 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.

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-present 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. Oh, if you aren’t the group class type, you have a whole host of guided meditation tapes provided by Kabat-Zinn.

Eventually, it will grow on you. 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 feel a lot about what is less than skillful that you 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: jkschl@uva.edu.
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, including multiple bronchosopies 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 kids that I cared for deeply. But would they 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 had two instead of three 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, 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, with the ups and downs, challenging and easy going times, sickness and health and 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 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 Hanley is 52 and has CF. She is a physi-

cian who is a Director of USACFA and is the President. Her 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

Birthdays

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NEW BEGINNINGS

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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 cortico-

steroids.

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 sup-

plements. Sunlight is best, as your body can 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 5,000 IUs 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.

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CF Roundtable Winter 2015

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CF Roundtable Winter 2015

FELO continued from page 1

MIA LEEDS
FOCUS TOPIC
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 outside 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 Kanashians made it chic to spell every word differently). 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 conceived with this wish, 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. It’s 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 my age and did twice-daily Mucomist inhalations (that smelled like rotten eggs, but also did). I fully played that we had three or four kids each, having one was just not an option. Me being an only child, I conceived with this wish, 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. It’s 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?

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 understand-able, as ours was her third home and she was only about six months old. So, I worked with a behaviorist when I decided to get my own. I exercised her in the morning and learned to occupy her with toys that kept her busy while my boyfriend and I labored away.

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.

After a few years, I moved back to my old apartment that my mom and I shared. My mom stayed on Long Island with Sadie and Molly. Sadie seemed content there, but was Dx’d anyway and we had to bring her back. We had been through so much together, I was never sure if I could handle being responsible for another dog, always time-consuming from waking to evening. Eventually, we adopted Ernie, who shared our house and became my mom’s best friend. She passed away in March 2016. So, I worked with a behaviorist when I decided to get my own. I exercised her in the morning and learned to occupy her with toys that kept her busy while my boyfriend and I labored away.

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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 be 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 at USSCF and is the Subscription Manager. His contact information is on page 2.

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.

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 they return to the body.

"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

My Mom and Me

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.
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 Dad for ice cream from the cafeteria.
He always said, “Yes.” I said, “Tea!” 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!

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MY MOM AND ME
FROM OUR FAMILY PHOTO ALBUM...

BRAD AND LAUREL AVERY.

BETH SIFIAN WITH JIM AND ISABELLA PASSAMANO.

JOELLE AND MARK LEVINE.

PAUL FELD WITH A STATUE IN VANCOUVER IN 2013.

AARON CUNNINGHAM WITH HIS NIECE AND NEPHEW.

JEANIE AND JOHN HANLEY ON THEIR WAY TO ALCATRAZ.

CYNTHIA DUNAFON, NEAR THE HORSESHOE MESA AT THE GRAND CANYON, OCTOBER 2014.
I t’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. Aaron arranged to have a goody basket (think chocolate) delivered. Our new star. Spotlight, please! 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 become too heavy. My BMI is 30 on a bad day, so I try to stay around that level for transplant reasons and overall health considerations.

What is your genotype? Homozygous Delta F508

Which areas does CF affect? CF has affected many areas of my body: lungs, sinuses (CFTRD), 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 conducting clinical trials now vs. 20 years ago? 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 instead of the monetary compensation. This could also be because years ago CF was more of a pediatric disease; pediatric patients have been given much hope from this improved gain.

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

When were you listed for transplant? In March of 2003 my FEV1 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 FEV1 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.

For 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 FEV1 is 36%. But I have had the work-up done again and am regular.
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 personal stories, research articles, advice and links to further sources of information built up over time.

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**What's your personal life like?**

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 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 day by 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!**

Jeannie 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 Jeannie.

**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 studies, research articles, and links to further sources of information built up over time.

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

Parion Sciences, a company dedicated to the development of novel therapeutic medicines, 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 (UCED), 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/2256445

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**Be compliant! Do your treatments and then some!**

**Have faith!**

We also provide a private support group on Facebook with more than 500 members worldwide. To visit our Website go to: www.cfmothers.com.

If you would like to join our Facebook support group, please e-mail Karen Vega at: kvega@usacfa.org.
Planning for a family is a life-changing decision, and having cystic fibrosis makes it that much more challenging.

Elizabeth Stone once said, “Making the decision to have a child is momentous. It is to decide forever which large and importantさいmade thing you will never accomplish.” 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 testes to the penis, to develop properly. Sperm is fully insured or self-insured. Fully insured plans follow state law. Self-insured plans follow federal law and are exempt from state law.

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 requires written or governmental action. 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.

• 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. Thus, a thorough strategy for how your financial resources will be affected by funding these costs requires you 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. Elizabeth Stone once said, “Making the decision to have a child is momentous. It is to decide forever which large and important thing you will never accomplish.” Planning for a family is a life-changing decision, and having cystic fibrosis makes it that much more challenging.

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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. 

[Sections discussing treatments and managing 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 70’s (shout out to deflazacort, Ketek), 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 indefi-

nite future. Sure, none of us on this page have a planet have a clue what to expect of the future. None of us would have had the knowledge of CF in those days to come up with CF in those days to come up with a college degree, marriage, having a family and a career. Getting a college degree meant we would have to 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 15 years.

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 us as well. On top of all of that, our predetermined cap was set long before we started treatments. My wife’s family didn’t warn us that 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 huge 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.

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

I recall my wife calling me from the doctor’s office with the kind of news that evokes tears rolling down her face. My first instinct was to make the best of it. 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 diffi-

cult 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. Even, each experience of sleep 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 bur-

den, I found the cry of a baby to be most effective at pulling me out of the deepest sleep.

Basically, I was a sleep-deprived zombie those first 16 months. My nights were a blur. We all 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 associ-

ated 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-

Continued on page 29
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 actually matters 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. 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 Zumba-ing, 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.

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

Anonymous continued from page 27

The author has requested to remain anonymous.
I mainly visited with my CF pals in the "teen room." I wasn't 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 "51" so I was actually mistaken for a teenager many times during hospital stays. But when I was a child, 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.

At a time when it seemed unlikely I would live long enough to be a mother, I dreamed of being able to breastfeed someone. I was figuring out how to keep my spirits up during long hospital stays. I had 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 (and some on 4 North).

I was actually mistaken for a teenager many times during hospital stays. In 1996 treatment options were very limited. It was the early days of home 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.

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 was 31 years old. At the time I was called on 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 the day party in two hours. The nurses wondered if I could help as they were short staffed and could not lift 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, I dreamed of being able to breastfeed someone. It was a dream come true.

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 of those present were wrappers 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 who needed the medicine they needed to fight CF. As we walked out of the teen room, every face had a big smile."

I dream 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, a mentor to serving others who 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.

I realized my spirits by figuring out how to make me better and in doing so I saved my life. Thanks to medicines like Pulmocyme and later Caplyson, 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.
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 very much appreciated 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 support and friendship. Reiner & Hatsuko Stenzel Pacific Palisades, CA]

Thanks for the wonderful Autumn 2014 edition of 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” within 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 31

do nothing.

On the darkest of days I remember 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 dreams 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 Arkansans Medicaid for our clients. By the time this article is published we will have saved our four clients in Arkansas a fourth girl became a daughter with CF. We found good 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.

Belt 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.

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/p6j5v3w

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

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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.

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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- Please notify us immediately of any address changes. Returned mail wastes money and delays mailings.
- We would like to act as a referral source for active adult support groups. Please send us your group name, leader’s name and phone number, number and age range of your members and geographical area covered, and we will add you to our referral list.
- Please let us know of the major occurrences in your life (e.g., marriages, births, completion of educational degrees or training, career advancement, transplants, anniversaries, birthdays), and we will print your information in *Milestones*.
- Share your ideas for *Focus Topics*, feature articles or any suggestions for improvements you may have to help make *CF Roundtable* more relevant and interesting to you.
- You can reach USACFA and *CF Roundtable* at anytime by e-mail at cfroundtable@usacfa.org
- Send your questions of a general nature regarding legal issues that relate to CF to our legal advisor: Beth Sufian, Esq., 712 Main, Suite 2130, Houston, Texas 77005. E-mail: CFLegal@sufianpassamano.com.
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An independent, nonprofit, international organization committed to improving the quality of life of transplant recipients and their families and the families of organ and tissue donors. For information, write to: TRIO, 2100 M Street NW, #170-353, Washington, DC 20037-1233 or e-mail them at: info@triweb.org.

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