CF Roundtable
A NEWSLETTER FOR ADULTS WHO HAVE CYSTIC FIBROSIS WINTER 2009

If I Had A Stem Cell

By Julie Desch, MD

Whatever you think about our former President, a friend of stem cell research, he was not. In 2001, Bush issued an executive order severely restricting federal funding for embryonic-stem-cell research to existing colonies of such cells. In response, California voters passed Proposition 71 in 2004, which provided three billion (with a "b") dollars (over 10 years) in order to:

#1 Establish the "California Institute for Regenerative Medicine" (CIRM) to regulate stem cell research and provide funding, through grants and loans, for such research and research facilities.

#2 Establish constitutional right to conduct stem cell research; prohibits Institute's funding of human reproductive cloning research.

Representatives from CIRM recently spoke at a meeting of CFRI, and gave an overview of stem cell science, as well as provided insight into how such scientific research could benefit those with cystic fibrosis.

What is a stem cell?

A "stem cell" is simply a cell that has the capacity to divide throughout life and can give rise to cells that become specialized and take the place of specific cells that die or are lost. Briefly, there are two types of stem cells, "adult" stem cells, and "embryonic" stem cells.

Adult stem cells act as a repair system for the body by replacing specialized damaged cells. They are tissue specific. An example is a stem cell from umbilical cord blood. This cell is primitive, but it can become only one of the multiple cell types formed by bone marrow. It cannot become, for instance, a kidney cell or a lung cell.

Embryonic stem cells are even more primitive than adult stem cells, and are able to differentiate into all the body's specialized tissues. Embryonic stem cells originate from an inner cell mass within a blastocyst. The blastocyst develops when sperm and egg fuse and divide a few times over about five days, prior to implantation. These stem cells retain the potential to become *any* type of tissue in the body excluding a placenta. As such, they are said to be "pleuripotent." (They have the *potential* to differentiate into any of the three germ cell layers).

Implications for Cystic Fibrosis

Ok, now that the biology lesson is over, why do we care?

Stem cell research is promising for so many disease entities; I can hardly list them all. They include multiple cancers, heart disease, diabetes, neurodegenerative disorders, acute spinal cord injury and many, many more. In fact, of the 229 grants currently given to 27 California institutions, only one specifically relates to cystic fibrosis. The goal of this particular study is to

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A WORD FROM THE PRESIDENT...

I think the majority of CF patients are like me, and after the first or second cold spell and the first couple inches of snow, we are ready for winter to end and spring to rise anew! Winter hit hard and early in St. Louis this year, and it's been simply darn cold ever since. I keep telling myself spring is just around the corner. I hope that's true.

Please see *Conversation Corner,* where **Darleen Boynton** has some additional insight from a previous issue on equipment that can make our lives a bit easier. Also in this section, **Michelle Savta** introduces us to a new website you may be interested in.

Our Focus topic is "Love, Dating, and Marriage". **Andrea Eisenman** and I reflect back on meeting our spouses and on pieces of our lives since then. **Dr. Jeanie Hanley** shares her personal sleep issues. (And I have to admit, while not meant to be a personally funny article, I smiled through the whole thing as it's a topic and issue my wife and I share almost every day.) **Debra Radler's** focus article will surely hit home for almost every CF adult. **Kurt Robinson** shares his story about love, and it's certainly refreshing to hear the 25-year-old's perspective. **Janice Tate** reflects on 20 years of marriage, thoughts about sex with CF, and surrendering selfishness. **Laura Tillman** completes the Focus articles with a unique perspective, and ends it with words of wisdom from her husband, Lew. In *Speeding Past 50,* **Kathy Russell** addresses our Focus topic from the perspective of a CF adult in her mid-60s, married for almost 44 years. We all should listen well to the insights she brings to us youngsters married half as long.

Isabel Stenzel Byrnes writes about facing your fears in *Spirit Medicine*. She discusses how a challenging swim created an immediate fear, and the several common sense steps she took to conquer it.

Dr. Julie Desch has two very interesting articles in this issue. The first is about stem cell education. Dr. Desch explains the basics and helps us all get a better grasp of the real issues here. In *Wellness* she tries to identify the key to happiness. It will be up to you to determine if she has her hands around this and if her observations are sound.

In *Voices from the Roundtable,* read and consume the short article from **Joni Murphy.** Often it is easy for some of us experienced CFers to dole out advice based on our experiences, but what would you talk about with Joni if she called you?

Finally, enjoy the photos from **Pammie Post** and the background commentary that goes with each of them. So often, Pammie's shots add an additional layer of brightness to the stories provided by everyone else in our newsletter. Keep them all coming so we can share with the rest of the adult CF community!

Ask the Attorney, A Deep Breath In and *Unplugged* are taking a vacation from writing and they will return in the next issue.

Peace,

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

MILESTONES

Please share the milestones in your life with our readers. Your successes and achievements may serve as a source of motivation for others in need of an infusion of "positive mental attitude" in the pursuit of their goals. Send us a note specifying your "milestone." Include your name, age, address, and phone number. Mail to: ***CF Roundtable*, PO Box 1618, Gresham, OR 97030-0519. Or E-mail to: cfroundtable@usacfa.org**

ANNIVERSARIES

Birthday

Donovan Couture
Colchester, VT
41 on December 23, 2008

Tom Dillon
Sun City West, AZ
75 on October 5, 2008

Ed Fleischman
Plainview, NY
67 on December 24, 2008

Karen Speer
Louisville, KY
47 on December 8, 2008

Wedding

Tom & Mary Dillon
Sun City West, AZ
43 years on November 6, 2008

Transplant

Michelle Compton, 41
Mountain View, CA
Bilateral lung
10 years on
December 3, 2008

Donovan Couture, 40
Colchester, VT
Kidney
2 years on
November 22, 2008

NEW BEGINNINGS

Wedding

Jonathan Quigley & Jessica Smith
Annapolis, MD.
Married on
June 28, 2008

LOOKING AHEAD

Please consider contributing to *CF Roundtable* by sharing some of the experiences of your life in writing. Read the **Focus** topics listed below and see if there are topics you might like writing about. In addition, humorous stories, articles on basic life experiences, short stories, art work, cartoons, and poetry would be greatly appreciated. We require that all submissions be original and unpublished. With your submission, please include a photo of yourself (as recent as possible) as well as your name, address and telephone number. Photos will be returned. Send all submissions to:

CF Roundtable, PO Box 1618, Gresham, OR 97030-0519. Or E-mail to: **cfroundtable@usacfa.org**

Winter (current) 2009: Love, Dating and Marriage.

Spring (May) 2009: Making Career Choices with CF. (Submissions due March 15, 2009) Choosing the right career can make a tremendous difference in one's life. Do you have any insights for our readers about how to make the right decision? Can you tell us of any pitfalls to avoid?

Summer (August) 2009: Becoming A Parent With CF. (Submissions due June 15, 2009) Do you have children or do you want to have children? Do you have any information about pregnancy or adoption that could help others? Do you have questions about pregnancy or adoption? Send your tips or questions to us.

Autumn (November) 2009: Gender-related Problems in CF. (Submissions due September 15, 2009)

SPIRIT MEDICINE

Fear Happens: Facing Fear

By Isabel Stenzel Byrnes

Death is not the biggest fear we have; our biggest fear is taking the risk to be alive — the risk to be alive and express what we really are. *–Don Miguel Ruiz*

A few months ago, I found myself alone on a beach in the Virgin Islands, staring down a small island about 300 yards away. I was told the best snorkeling on St. John was around the waters of that island, Waterlemon Cay. The plethora of colorful sea life tantalized me. I delighted in the prospect of adventure, to prove that I could make it to the island. I told myself, "I will do this. I will swim to that cay." Yet, I was afraid.

As I gazed at the choppy waters, I wondered why I was afraid. The first step to facing my fears was to name them. Then I'd know what I was dealing with. I was alone. The waters were rough and deep. I rarely swim in open water. I had no fins. If I saw large sea creatures around me I would surely freak out. What if they bite me? The bottom line: I was afraid of dying in that water.

I began to ponder how I had been dealing with a fear of dying all my life. In his last *Unplugged*, Rich DeNagel also confessed his fears of dying, reminding me that many of us with CF have this fear. Some CF parents have asked me when is the right time to tell their children about the life-limiting aspect of CF. Parents don't want to induce fear of death in their child. The truth is, fear is an inevitable and normal part of the human experience. Parents cannot protect their children from fear. Eventually, kids will learn they can die of CF. I tell parents to get in touch with their own fears of mortality first and then start an age-appropriate dialogue with the child. But the real issue is how to help a child – and an adult – face their fears.

We doubt our own strength when we face our fear. When my healthy friends say, "Oh, you're so courageous," I just roll my eyes. They perceive those with illness as having some mysterious fortitude that they do not have. As far as I am concerned, I was born with a disease and just live with it.

But this comparison even happens among people with CF. Recently, a healthier CF friend undergoing a painful procedure wrote me, "How will I be able to handle transplant pain when the time comes? I am not strong like you." I believe courage is a quality that all human beings possess deep within, but few know they have it. They just have to access it.

> *"The first step to facing my fears was to name them."*

ISA STENZEL BYRNES

We need courage, but we also need fear. Fear is a natural human emotion. Fear is a signal that something is off, or not right, and needs to be tended to. Of course, fear that leads to panic, irrational or destructive behavior and immobilization is a problem. My wise friend, Nahara, warns, "When fear paralyzes you, it inhibits your transformation."

Most of the time, fear is a natural protective instinct, an adaptive mechanism. Fear alerts us to possible dangers, so we can get out of harmful situations. Fear and anxiety incite action. If we fear burglars, we lock our doors. If we fear the dark, we keep the lights on. If we didn't fear dying of CF, we wouldn't be doing all these treatments and taking care of our bodies. We wouldn't be fundraising to find the cure, so we can live a normal lifespan. Life is a sacred gift, and we want more of it. Our fear of dying is a normal survival instinct.

I have many other fears. I am afraid of going back to work, which might expose me to a lethal infection. I am afraid of losing my loved ones. I am afraid of dying alone. I am afraid of rejection, even judgment.

Honestly, I am sick and tired of being afraid! So how do I become braver? I want to cultivate courage.

Back on the beach, I thought about my options: I could bury my head in the sand and avoid the thought of swimming; I could sit on the beach and yearn to swim but never go for it; I could run madly into the water, cursing my fears and just swim, damn it! Or, I could think about my fears, allow myself to feel them, but move forward in the water anyway. This is what I did. There were several mental exercises I used to cultivate the courage I needed to face my fears.

First, I got informed. The ranger had said there were harmless sharks, turtles and sting rays around the cay that ignored humans. Unlike the nearby beaches that had red flags posted indicating hazardous swim conditions, this beach was a protected bay. Those were the facts.

Second, I evaluated my current physical strength. I was trained in swimming and could handle the distance. I evaluated the wind and waves, and decided they wouldn't overwhelm me. I took precautions- I swam with tevas so I could walk on the shore without injury to my feet. Blood sugars were good. Lungs were good. I trusted my body.

Third, I sought support. During my contemplative period, a family approached the beach from a trail and prepared to snorkel near me. I delayed my swim until they were in the water. As they swam farther out, I swam somewhat alongside them, respecting their privacy but imposing my presence in a subtle way. If I had trouble, I could call for help, and vice versa.

Fourth, I paid attention to my breathing and thoughts. With a firm bite on my snorkel tube, I used my mind to calm my breathing. If my breathing was regular, deep, and controlled, I wouldn't panic, even when I couldn't see the bottom of the ocean floor. I talked to my breath, thanking it, trusting it. I also controlled my inner dialogue. My own scary thoughts about the "what-ifs" are often worse than the reality itself. My friend reminded me that FEAR stands for "False Evidence Appearing Real". The real enemy was my head, not the sea creatures or current.

Fifth, I sought spiritual guidance. I knew I wasn't alone, but in the presence of a power greater than myself. I prayed for the strength to swim without cramps or hyperventilating. I knew my success wasn't up to only me; there was fate, unpredictable circumstance, and perhaps a master plan that was going to unfold. I let go of my own control. I let my God guide me.

> *"I believe courage is a quality that all human beings possess deep within, but few know they have it. They just have to access it."*

Sixth, I practiced acceptance. Having survived several near death experiences, I thought of the possibility of dying while snorkeling. If that's the way I'm meant to go, I accepted that outcome; knowing I lived fully in the moment and took the risk to face my fear of death with eyes wide open. I had lived lovingly and my love would support those left behind. I had no regrets. I then laughed at my own folly of taking this swim so seriously, yet it was just for fun.

Ultimately, I swam to the cay. The water was rough and my muscles burned. At one point, about twenty feet under me was a 4-foot-long shark. This wasn't false evidence! A surge of panic hit me, but then I stopped. I looked at the shark's zigzag squirm. He was a creature just like I was. Existing in time, like me. I reminded myself that "there was nothing to fear but fear itself". Nonetheless, I picked up the pace and was relieved to make it to the cay.

The snorkeling was indeed impressive, with schools of hundreds of small yellow and blue fish and huge rainbow-colored parrot fish, anemones, purple urchins, and bright orange coral. All of this beautiful life, including the shark, would come and go, just like me.

On the return to the island, I passed a massive ray under me as well. I felt another swell of terror as I remembered the Crocodile Hunter's death, but then told myself I wasn't going to wrestle it like he did. When I made it back to the island, I thanked God. And I felt proud. I did it! I didn't let fear paralyze me.

My last mental exercise to face my fear was to share this story, not to show off any bravery, but just to express my experience. To be honest, I have a natural need to have my fears acknowledged, and am comforted if I'm told that many people in my situation would be fearful, too.

That's what we have to do with our fears of dying. We just have to live. Truly, deeply, passionately, lovingly live. So that when our time comes, we will have no regrets, we will feel proud of that long swim, of the beauty we saw, of the fears we overcame, of the support we received, and we will be more welcoming of the safety of the other side of the shore. ▲

Isabel is 36 and has CF. She is a co-author of "The Power of Two: A Twin Triumph over Cystic Fibrosis". She and her husband, Andrew, live in Redwood City, CA. She invites spiritual writers to share their 'spirit medicine'.

SPEEDING PAST 50...

An Older Perspective on Love, Dating and Marriage

By Kathy Russell

At my age, I'll be 65 in April, dating is a thing of the long past – or is it? Even though my husband, Paul, and I have been married almost 44 years, we still have "dates". We never have been big on "going out" a lot, but we love to have dates at home.

Every Saturday night, and sometimes on other nights, we have a movie date. I'll get a movie from the library (free) or from a rental place and we sit with big bowls of popcorn, glasses of ice water and a miniature Nestlé's Crunch bar each, and watch our movie. We can adjust the sound to our liking and there are no people talking (other than us) or stepping on us as they go in and out of the row. If we miss something, we can run the movie back to see what it was. Such luxury.

We don't have to worry about anyone coughing on us or dropping anything on us and we can dress comfortably. We love old movies and can see them in all their glory.

You might be wondering what this has to do with CF. Well, let me try to explain it. People who date or marry people that have CF have to learn how to accommodate CF in their everyday living. For instance, I don't like to go out in crowds, especially during the cold and flu season. So Paul has learned how to make life interesting, without having to leave home. He makes it easy for me to have a full life, without getting too tired or being exposed to harmful "bugs".

We still go out to eat with friends and we still go shopping, although not too often because I don't like to shop. We do go to a few "functions", although not as many as we used to. We take drives around the beautiful, scenic area where we live. We enjoy the great outdoors, at home.

We haven't always been "home bodies". When we were younger, I worked fulltime and had loads more energy than I do now. We traveled extensively. We flew all over. We never got below the equator, but I can live without that. I have wonderful memories of trips to Asia, Europe and the countries of North America. We would go to Hawaii a couple of times a year. (Since we live in Oregon, that was an easy trip.) It was great! Now I use oxygen (O_2), when I fly, so it isn't as easy as it once was.

We plan our trips with enough time that we don't have to travel too long in any one day. For instance, when we went to China, we flew to Hawaii for a few days to visit friends. Then we flew to Tokyo and spent a night. From there we went on to Hong Kong. We had to be in Hong Kong for a certain length of time, before we could venture into China. When we came home, we again spent time in Hong Kong, Tokyo and Hawaii. This made it possible for me to cross about 12 time zones without getting too tired. If Paul had been traveling without me, he might have done the trips in one day, each.

PAUL AND KATHY RUSSELL AT THEIR WEDDING.

There have been times when he has had to travel alone, because I just couldn't make a trip. He never complains about it. He is able to cover more ground in less time and he usually takes photos so that I can see some of what he saw.

Paul has had to make other adjustments because of my CF. He did not become a father. When we were of the age when most people have children, there was no way to ascertain if he was a carrier, and we would not take the chance of having a child that had CF. Because of how my health was, at that time, we did not consider adoption. If I remember correctly, we could not be considered as adoptive parents anyway, because I had a "terminal" illness. We have six godchildren and have been content with watching them grow and mature.

I had to stop working when I was 31 and that made a big difference in our "game plan" for how we would live our lives. Paul gave up the good job he had in Southern California, took a demotion and returned to Oregon, because we really couldn't afford to live in that area on one salary. Oregon was more affordable and I feel better here.

Paul does all of the "talking" with our health insurance company. He spends long periods on hold, waiting

to question, clear-up or complain about some decision that the company has made. He never complains about all the time and energy it takes for him to do this. He is an absolute *Master* at it.

As I think back to when Paul and I were dating (since it was more than 40 years ago, it is really ancient history,) I remember that we each took the time to interview the other. We asked all kinds of questions and had learned a lot about each other, including the fact that I have CF, long before we got "serious" in our relationship. We found that we had a lot in common, even though we were raised 3,000 miles apart. We became best friends. May I suggest that it always is a good thing to marry one's best friend? It certainly has been good for me.

Paul has learned when to offer assistance to me, when I am coughing, and when to leave me alone. We have our own form of "shorthand" that allows us to communicate with little talk. A look or a gesture can signal that help is needed or that I am okay. He is understanding and sympathetic.

As we grow older together, we find that CF isn't as overwhelming a part of our lives as it once was. Most of our friends are suffering the "joys" of aging and they are having health problems, too. Somehow, as one has leukemia, two others have pulmonary fibrosis, several have heart troubles and too many have Alzheimer's, Parkinson's, cancer or diabetes, CF just doesn't seem to be such a big deal. I am used to it, Paul is used to it, and we can manage.

When I turn 65 in April and go onto Medicare, we will have a whole new round of "battles" to wage. Paul will spend time talking with various people, in order to get all my meds and treatments approved and be sure that they are where I need them, when I need them. I thank him, in advance, for this.

With all the new advances in medications and treatments that there are for people who have CF, there is no reason for it to be a deterrent in anyone's life. It shouldn't keep anyone from getting a good education, having a normal love life, having a fulfilling career, and living life to the fullest. It may take a little adjustment and fitting, but it is doable.

Anyone who loves someone who has CF should be able to expect a long and interesting life together, with that person. Of course, there can be bumps along the way. Everyone should stay flexible and should make allowances for illnesses, hospitalizations, and various other health problems. With good planning and lots of love, all things should be possible for us. After all, if I could find "the one man in the world for me" in a soda fountain, then anything can happen. But that story is for another time.

This issue of *CF Roundtable* is the first of our 19th year of publishing. When we began, few could have imagined that this many years later we still would be going strong. We have weathered many storms and still are able to produce a publication that many find interesting and useful. *AND* we still ask only $10 per year as a donation to help with our expenses. I think that is pretty good.

Another adjustment that my dear husband has had to make is putting up with me planning our lives around the publishing schedule for *CF Roundtable*. He also had to get used to living with all the back issues of *CF Roundtable* and helping me with the stuffing of envelopes and labeling and mailing of *CF Roundtable*. He has been an invaluable asset to USACFA and, not to forget, to me. Thanks, Paul, you're the greatest! ▲

Kathy is 64 and has CF. She is a Director of USACFA. Her contact information is on page 2.

Announcements

VOLUNTEERS NEEDED FOR STUDIES AT NIH

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

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

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

FOCUS TOPIC

LOVE, DATING AND MARRIAGE

That's Amoré!

By Jeanie Hanley, MD

On the list of marriage virtues is communication, communication, and communication. Listen, talk, understand, talk and listen some more! Oops, have I forgotten the introduction? Seeing the focus topic immediately compelled me to write down the first thoughts that permeated my brain. The bottom line is after our 22+ years of marriage, we are still together because, I believe, we have been able to overcome many of the challenges that CF presents to our relationship by listening to each other, effective communication and working the kinks out without becoming upset (most of the time).

One such challenge that has occurred fairly recently, is that, well, embarrassing as it may seem, I snore! Now that I have blurted that out, I'm going to take it back, sugarcoat and qualify it. Here it goes: I didn't always snore, and, to be quite honest, it's not classic snoring, really. It's more like a symphony of wheezes, murmurs, rattling, sometimes hacking and sputtering, sometimes snorting. I know, unfortunately, because sometimes I wake myself up!

These sleep disturbed nights come and go for long periods depending upon how well my lungs are functioning and what medicines I'm taking, namely steroids or IV antibiotics. To alleviate any worries, there is no apnea (my oxygen saturations are not falling while I sleep and, hopefully, they never will), and it's not blow the house down, sawing wood, guttural noises. They're just annoying and irregular enough to wake my husband up for weeks at a stretch.

My husband has put up with this in various ways. At first he will gently nudge me to change positions, which sometimes helps. After a while, in my stupor, or after too many nudges, we both become irritated. If the volume crescendos still, he simply starts sleeping in the extra room. When this occurs more and more, I begin feeling a little depressed. At this point, sleep deprived or not, we have to have a heart-to-heart.

First, I had to face the fact that I make irritating little (and, sometimes, big) breathing noises while I sleep and, second, we had to find a solution so that we could still sleep in the same bed. To accomplish this, we had to explore the causes and determine if there was treatment available that I could tolerate. Although it is reassuring that the cause is not obstructive sleep apnea, at least this could have been treated effectively. Instead, this sleep-interrupting breathing turns out to be due to secretions that settle in various locations of the respiratory tract from the lungs through my vocal cords to my sinuses. When I require high-dose steroids or have had a recent "tune-up" (and, hence, fewer secretions), then many of these noises miraculously disappear.

Knowing the cause, in this case, did not leave us with an obvious solution, except to try to stay as well as I could by adhering to my daily treatment routines. Regular exercise, nasal saline washes, yoga, herbal and other alternative therapies, while beneficial in many respects, were not helpful to lower the nighttime chorus entirely. I have noticed medications for sleep and alcohol tend to dry up secretions throughout my respiratory tract and while they may reduce the snoring at night, the detrimental effect on the lungs is too costly. Staying on steroids and all of its immediate and potential side effects just to stop these noises was not a viable treatment option.

JOHN & JEANIE HANLEY IN FLORENCE, ITALY.

The final treatment option was getting down on my knees and praying! My prayers to stop snoring and be able to sleep peacefully with my husband were, well, kind of answered. I guess I was not very specific with my prayer request, but who am I to look a gift horse in the mouth. The answer came from the most unlikely of places, my annoying next-door neighbor (the guy on the west side of our house, because the couple on the east side are terrific- just in

case you were wondering). Anyway, he moved in about five months ago, and has a "soothing" habit of leaving his TV on at full blast throughout the night. We may enjoy old reruns now and then, but not at night while trying to sleep. Did I also mention his two dogs that never stop barking?

After getting the canine situation under control (he finally let the poor dogs sleep inside at night), we were still left with the blaring TV situation. Although his TV room is on the first floor and our bedroom on the second floor, the sounds of *Dragnet* and some unmentionable shows traveled perfectly in a swirling, curving fashion right through our bathroom windows into our bedroom, through our pillow-covered heads and earplugs, to our eardrums.

Nothing seemed to work – closing windows (but then it was too hot), putting on the air conditioning (but then it was too cold and the sporadic turning off and on of the AC woke us up just as much, and then there's the accompanying electricity bill). Just when we felt he needed another one a.m. visit (yes, that occurred when we thought the noise was just the dogs), we inadvertently found the answer. So simple…a fan…and cheap!

Since it was the summer and starting to become fairly hot, we broke out the fan initially just to cool us down. Turns out that this little fan gives off quite a loud hum, but it was just loud enough and constant enough to completely drown out the sounds of *Bonanza* reruns and *Transgender Women in Prison* TV shows from my neighbor and, in the process, lull us to a nearly blissful sleep. And, guess what? The humming also drowned out the bothersome noises of you-know-who. We finally found a solution for both of us to sleep well when my nighttime sleeping antics begin.

Sleep – and lots of it - is obviously very important and critical to the health maintenance of anyone with CF and their bedtime partner or roommate. I believe all of us would jump through hoops of fire if it meant we would be able to find the perfect antidote to a lousy night's sleep. And since it is estimated that three of four adults with CF have significant sleep disturbances, there are quite a few of us who would be standing in the hoop line.

With regard to relationships, sleep is also key. Our sleeplessness affects our partner or roommate and their ability to sleep well. Just as important, that quiet time right before my husband and I doze off for the night is often the only time we get to talk about issues affecting each other, our three teenagers and everything else going on in our lives. If we are both irritable from lack of sleep and/or do not sleep in the same bed, then that opportunity for communication is lost.

Occasionally, my husband still needs to nudge me even when I am relatively well. During those nights when I know my array of breath sounds has been particularly prominent, I am appreciative in the morning for his not tossing me off the bed altogether or for not suffocating me with a pillow. Now that's love. ▲

Jeanie is 46 years old and a physician with CF. She lives with her husband and three teenagers in Los Angeles.

Mailbox

I wanted to compliment everyone on another fantastic newsletter! I especially enjoyed the "Photos of Autumn" by Pammie Post. It was a treat to see the "little red lighthouse" pointed out in one of the photos, since my children enjoyed that book.

Thanks again for a wonderful publication.

Debbie Moore
Portsmouth, VA

I love your newsletter and appreciate everyone sharing their experiences with the CF community. Keep up the good work and I hope you all have a safe and happy Holiday and a healthy New Year.

Gayle Greenberg
Potomac, MD

Thank you so much for your always informative newsletter I'm reading. I never fail to be a little emotional and oh so proud of all the extraordinary men and women who contribute regularly, and who by their life example bring comfort and hope to so many.

Phyllis Kossoff
New York City, NY

We really like and look forward to receiving *CF Roundtable*. It is very informative. Thank you.

Joanne Brockmiller
Union, MO

Enclosed is a check for another year of my subscription. Great articles. Very well done. Thank you,

Doug Johnson
Mundelein, IL

What I Know Now

By Janice Tate

On August 6, 1988, we, Robert (Bob) Tate and Janice Benning, were married at St. Domitilla Catholic Church. I was so happy I felt like I was floating on air. Since I have cystic fibrosis (CF), I was living out a dream I never expected. But Bob, who also has CF, didn't see our health as an issue as big as I did. Maybe it's because he was diagnosed at age 9, but I was diagnosed at birth. Also, I was more aware of CF's impact on life span. Five years before my birth, one of my sisters died from CF at one month old. I confess because of my focus on limited life expectancy, I could not imagine that both of us would still be alive to celebrate our fifth anniversary. To be celebrating our 20th wedding anniversary is amazing!

Over the years I have had thoughts of, "I wish I had known then what I know now." One lesson that I learned is that *love* is a *verb* and *a decision*. It's true that love is also an emotional feeling; but that will not sustain a committed relationship. After we were married around five years, I had a sense, "Is this it? I'm bored." When I recalled the reasons I was so certain on our wedding day that we were meant to be, I realized only the emotion had changed. Not the reasons. So I decided then I would love Bob even without the emotional "high". The sweet irony is that some time after I chose to make that sacrifice, "the loving feeling" returned. It was different, but affirming and deeper.

Something else I wish I had known better when I was first married was the beauty of human sexuality. Our bodies, male and female, are incredible creations and sex between a husband and wife is sublime. I wish I had been taught in health and biology classes that sex is much more than satisfying an urge. It would have been nice to know sooner that an attitude of openness to the many facets of sex including procreation, bonding and pleasure is good for a couple. That attitude of being open is a generous attitude which helps to avoid the danger of using one's partner as an object to fill a desire. That generous attitude promotes cherishing your spouse.

JANICE AND BOB TATE AT DINNER IN ARUBA IN SEPTEMBER 2008.

God created sex to be pleasurable for several reasons. Perhaps an obvious reason is so that people will do it…and have babies… so that human life will continue. It is also a powerful bonding action. Did you know a woman actually secretes a hormone during sexual intercourse that causes her to bond with her partner? That's a great gift during the honeymoon…and beyond, when you discover your spouse is not as perfect as you imagined. It's not so great for casual sex.

The "marital embrace" (i.e.: sexual intercourse between a husband and wife) is a pleasurable opportunity to generously reaffirm our vows to love one another. A big part of being generous with your spouse during the marital embrace is the promise that if the miracle of conception occurs, you will welcome that life. But if getting pregnant is dangerous or is a burden because one or both spouses deal with a chronic health condition like CF, there is a very respectful way to avoid pregnancy.

Have you heard of NFP? There are no drug interactions to worry about. It is totally safe for the environment. If done correctly, it is, at the least, as effective as chemical birth control. It works like this: the woman gets to know her body's fertility signs and the couple who decides that they cannot have children abstains from sexual intercourse during her fertile time. I have heard the most common side effects of Natural Family Planning (NFP) are growing in greater appreciation for your own body and for your spouse.

In order to learn NFP, a couple will need to attend classes or do a home study. Because of medications, a

woman with CF may need special consultations to access the impact of the medications on her fertility signs. *An important note for women with CF who would like to become pregnant: our thick secretions often make us less fertile. But NFP can assist you in achieving a wanted pregnancy through tracking your fertility signs.* For more information about NFP, check out the Couple to Couple League International at 800-745-8252 or www.ccli.org.

Another area of marriage that I understand better now is the vital role of helping each other to become the best people we can be here on earth. It is true that simply through being married, I have become a less selfish person. In the Spring 2008 issue, Kathy Russell mentioned that her husband has helped her to grow in many virtues, like empathy, compassion, understanding, patience, tolerance, forbearance, and equanimity ("even tempered"- I had to look that one up!)

Sometimes achieving that growth hurts more than other times! Following one another's good example is usually the less "painful" way to grow. Having to surrender our selfish impulses is often the more challenging way. The easy way: We watch each other take good care of ourselves and are reminded that we need to do our treatments. More challenging: In the past I have expected Bob to do something for me because I was tired. But because of his CF, he had to take care of his own health. And as it turned out, I was able to handle what I thought someone else should do for me. Watching Bob take care of himself and having to surrender my desire to be taken care of have helped me grow out of my victim mentality.

Helping one another become the best people we can be is ongoing. Recently we went on a fabulous trip to Aruba to celebrate our anniversary. (Yeah!) As usual Bob let me make most of the choices, like where to eat. His example of generosity made me notice my own selfishness and that I was insisting on my way. So in an exercise of generosity, I let go of my expectations and let him choose our next dining experience. Wouldn't you know it! That meal was the best one out of our whole trip!

> "Watching Bob take care of himself and having to surrender my desire to be taken care of have helped me grow out of my victim mentality."

When we were engaged someone warned me that I was in for "guaranteed heartache" by marrying a man with CF (not because she knew something about Bob I didn't know!) She was concerned about either of us having to watch the other one die. Unfortunately the reality of married life is that no matter to whom you are married, chances are one of you will be left behind. I don't even want to think of the emotional pain that could cause. I suspect it will be incredibly difficult: more so now after 20 years of bonding. But I trust that all the potential pain cannot outweigh the gifts of our years together as husband and wife! ▲

Bob and Janice are 44-year-old adults who both have CF. They live in Streamwood, IL with Juji Mei, their loving pooch.

STEM CELLS *continued from page 1*

develop a cell line that carries the cystic fibrosis mutation.

Don't despair however, many of the grants may not be specific to CF, but are extremely important in learning more about stem cell biology, how embryonic stem cells grow best, and how to make them differentiate into a desired cell type. It's such a new field that, basically, it is all important to us, even if it has nothing to do with chloride transport!

Think about what a stem cell line can do. Remember, these are cells growing in a dish that are genetically identical and can reproduce over and over. Now, imagine a magical cell line that carries the △F508 mutation. This cell line would not be from a mouse…or a pig…or a ferret. It would be *human* and would presumably mimic exactly what happens in you and me. Scientists could learn vast amounts of information regarding CF biology with such a cell line. Multiple potential therapeutic agents could be tested on such a cell line, with the promising ones going directly to clinical trials. The efficiency of such a drug testing mechanism is breathtaking (no pun intended). Finally, imagine coaxing a "normal" cell line (one with no CF mutations) to form *lung tissue*. What if some bright young scientist figured out how to deliver such cells to the damaged airways of a CF patient?

Obstacles

Stem cell research faces more obstacles than just the Bush administration. First, the tanking economy suggests that funding *any* research may take a back seat to, say, feeding people. Second, the FDA needs to approve all studies, and to date, finding appropriate safety guidelines is not proceeding quickly. Finally, the passage of Proposition 71 has galva-

Continued on page 13

My Partner In Life – Kristi

By Paul Feld

It was the spring of 1990, and a young woman with a spring in her step has made her way up to my department. My eyes met her and followed her down the hall, where she stopped to talk to a peer of mine. "What a catch she would be for someone," I thought. We exchanged a quick glance, and I later asked where she worked. "Patient Accounts," my co-worker said. Physically, she was just a few feet away, but under me by one floor. "I hope I get a chance to work with her," I said playfully.

That chance came a few weeks later when our hospital chose a team to implement their next Patient Accounting application. Kristi would work as an analyst in patient accounting, and I would end up being the database administrator on the project. We would end up meeting with our vendor quite often, and between the two of us, we would have I/T or Patient Accounts well covered.

I had just been separated from my wife, both of us in our first marriage. While we had an uncontested divorce, it was not easy for either of us. Eight years earlier we had decided to adopt a one-year-old girl, and we knew she would probably suffer more than either of us from our divorce. My first wife was trying to deal with my CF, and all that went along with it in the early nineties. No home care, lots of tune-ups, and even more respiratory problems. She knew I had just a few years left, and that thought, alone, scared the heck out of her – raising a pre-teen on her own. She asked for a divorce, thinking life would be much better without me.

Kristi and I talked a lot about my life, my disease, and life in general. She was then, and always has been, a great listener. I confided many things to her, going into great detail about what it was like to live with an adult with CF. She would listen and smile; and over time, grew to love me. From my perspective, love happened almost instantly. As she would listen to my problems and issues, she would suggest options for solutions or simply nod in understanding, rather than say, "Wow, I don't know if I could deal with that." Just six months after my divorce was final, Kristi and I married on June 1, 1991.

At the time, I was a 33-year-old CF adult, and the prospects for a long life were certainly not in my favor. Statistically, I should not even have lived this long, so for Kristi to want me for a husband blew many people away. I was a six-month divorced adult with CF with a nine-year-old girl to raise. Kristi was a 30-year-old single adult with a good job and great prospects to do whatever she wanted to do. "What the hell is she thinking?" most people thought, including most of her family I'm sure.

> "Statistically, I should not even have lived this long, so for Kristi to want me for a husband blew many people away."

The first couple years were not easy for us. The custody agreement for my daughter, Sarah, was that she would live with us for one week and with my ex-wife the next. While this worked out much better for both sets of parents for planning purposes, it was not good for Sarah, who would have to adapt her lifestyle and culture on a weekly basis for the next seven years. By year eight, she could not tolerate it any more, and chose to live with Kristi and me. I can't pinpoint a specific reason she made that decision, and I'm sure she weighed the pros and cons, but I am certain Kristi was a factor. It's possible neither of them would agree with me, but as an objective third party I know that everything Kristi did, as it related to Sarah, was in Sarah's best interest. At times I know she was much stricter on her than I would have been, but it was right. She always seems to know what is right, even when it's tough love.

When Sarah went off to her junior year in college, it was the last time she would spend continuous time living with us. She decided to spend her summers in Kansas City with her boyfriend, Jason, and they have been together eight years now. During that time, about at midpoint, I had my bilateral lung transplant. Kristi has been nothing short of amazing during those eight years, and I truly believe our love for each other has continued to grow stronger every day.

As I have stated in previous articles I've written for this newsletter, her ability to care for and nurture me through the transplant experience has been one of the greatest blessings I could ever receive. It's absolutely one of the toughest jobs a caregiver can be tasked with; and if the caregiver is your spouse, it can put strains on a marriage that the marriage has never seen before. Kristi was simply out-

standing, tolerating my mood swings, physical recovery, her job, my family and, mostly, me. I certainly would not have been able to survive the recovery process without her; and I would not have wanted to care for someone in my condition for the months that followed my transplant. It's almost a joke to say it was a full-time job, because it was a 24/7 job, and I don't believe anyone in my immediate family could have pulled it off.

It truly does take almost a year to fully recover from that experience, and the two of us have grown even stronger since then. As with most couples married at least 15 years, you can anticipate every reaction your partner might have to any given situation and be either a panacea to the anxiety or a push into further happiness.

As the last few years have passed, I continue to be amazed at what Kristi continues to take on, besides me, to make this little world of ours a better place. She continues to support me, in both my local and national CF activities. She is very active in her church activities, helping fellow parishioners in their daily struggles, whatever they may be. She is currently working as a hospice volunteer, making food every week for her patient and visiting her as often as she can. She makes friends, and genuinely works to keep long-standing friendships alive and flourishing, simply by taking the time to do so. Oh, how I wish I had done that with many of my "old" friends.

How lucky and blessed have I been to have seen that young woman walking down the hall in my department in that long, blue flowered dress 18 years ago? Of all the blessings I've received in my life, Kristi is certainly at the top, and I just can't imagine my life without her. ▲

Paul is 51 and has CF. He is a Director of USACFA and is the President. His contact information is on page 2.

STEM CELLS *continued from page 11*

nized opponents at the state level. Stem cell research is a very divisive and controversial issue. Some say that these leftover blastocysts from fertility clinics are "humans" and therefore harvesting their "inner cell mass" is akin to murder. In fact, just last month, Colorado voters were asked to define a "person" as any human being from the moment of fertilization. This was defeated, but how many more times will this come up? Finally, only 1 in 30 blastocysts generate a cell line with current technology.

What are the "CF" specific hurdles? Let's be clear. It isn't simple. For one thing, the one funded study has not yet received a blastocyst with CF (then, remember the 1 in 30 thing). In addition, it isn't easy to convince CFTR-able stem cells to become lung tissue. Then, it isn't clear how to get such cells (if they existed) to damaged, scarred lung tissue.

So there is a ways to go…

What's NEW in 2009?

You guessed it! A brand new President, and likely, a brand new executive order will reverse the prohibitive order from "W." The NIH (National Institutes of Health) funding will now become available to institutions all over the country, not just California. Research in this area will increase exponentially.

Even more exciting, researchers in Toronto have recently described a method to "induce" pleuripotent (remember this term…embryonic stem cells are pleuripotent) stem cells from *skin*! What this means is that a leftover blastocyst may not even be needed. Controversy, be gone! Not only that, but rejection issues, be gone! (Yes, rejection does seem to be an issue with embryonic stem cells…DNA matters). If you can convince your own skin cells to dedifferentiate back to a pleuripotent cell, and then manage to make it differentiate into, for instance, beta cells of the pancreas, no more diabetes and no rejection!

Stay tuned. ▲

Julie is 48 and is a physician who has CF. She writes the "Wellness" column for CF Roundtable.

CF Legal Information Hotline

If you have questions regarding health insurance coverage, Social Security benefits, Medicaid, Medicare or employment rights, contact The CF Legal Information Hotline at 1-800-622-0385. All contacts are free and confidential. The Hotline is proudly sponsored by the CF Foundation through a grant from Novartis Pharmaceuticals.

Beth Sufian, Director of the CF Legal Information Hotline, says, "As Director of the Hotline, I have seen an increase in calls since September 2008, and the ensuing decline in the economy. It is important for people with CF to understand ways to access insurance coverage, if the need should arise, and what their rights are in the workplace."

Beth's *Ask the Attorney* column will be back next issue. Until then, she encourages people with questions to contact the Hotline.

My Unconventional Journey through Love...

By Debra Radler

You date. You fall madly and passionately in love. You marry. You may have children. You weather the storms and you share the triumphs. You journey together through changing jobs, houses, bodies, ideas and attitudes. And at the end of the day the person who made your heart go pitter-pat a lifetime ago is there with you to hold your hand, and encourage you to let go and journey on to your eternal life. That's the picture we all have, isn't it? That's the way it's supposed to be, when you think you'll be around to share your life with someone.

But what if you don't think you will be around? What happens to you "relationally?" I can only share with you what happened to me. And though many of you have already undertaken what I would like to call the conventional journey, mine has been anything but conventional. Some of you may be able to relate to me and others will wonder, as my mother does, which particular planet I inhabit.

I'll begin my ongoing journey by sharing with you the way I adapted to the scariness of being diagnosed with CF and being told I would die young. I think it's important to note, because it clarifies the insanity. I became very free spirited, peppered with quite a strong will. I could engage easily, was completely impulsive, was outwardly self confident, inwardly morbid, and, most notably, able to emotionally detach in a heartbeat. As a matter of fact, I rarely allowed myself to emotionally attach at all. The heart was protected with a thick coat of armor from entry or exit of any feelings slightly resembling vulnerability or love. I cocooned myself in shallowness.

I don't know if it was readily visible to those around me. I appeared very approachable and eager to engage, but the extent of the engagement was severely limited. I had thick emotional walls. This really isn't rocket science. Why would I want to set myself up for either rejection from someone I might love because of this disease, or worse yet, hurting those who loved me by dying on them? It was so much easier to just float through life with a layer of "fun" wrapped around myself, and leave the emoting to those equipped enough to handle it. Time would prove that "easier for me" was not always so easy for those who cared about me.

The dating game was a breeze for me. I loved the initial interaction with someone. I loved the chase. I loved the fact that it was ok to be attracted, to kiss, to hold hands, and to feel "in love" without really having to share too much. I was always most comfortable at step one of the relational journey. During my late teens and early 20s I dated many young men. I wasn't a loose girl by any means, since my strict Catholic upbringing kept me in place; but I was definitely a flirty girl. I'd be madly in love for about a month, and when I would feel myself start to become vulnerable, it would be over for me. No huge investment, no sharing of intimate details — time to move on. I would dump them with no damage to my heart. During that stage of my life, I never had a serious boyfriend. I simply was not yet emotionally equipped to take that route.

DEBRA RADLER AND ADRIAN GULINSKI

I did, however, find myself attaching to a serious boy "friend" during my freshman year in college; serious in that he was a contemplative, soulful, somewhat dark young man. Despite our completely opposite natures, we became best friends during our four years in college; and for as much as my shallowness helped him become a

bit more socialized and appreciative of some fun, his soulfulness and loyalty taught me the value in allowing myself a little depth.

He was one of the first people with whom I shared my illness. Until then, it had been my dark, little secret. I wasn't afraid to share with him, because I trusted him. He was genuinely caring and not at all threatened by this disease that was threatening me constantly. We dabbled over the years in something deeper than friendship, but somehow our timing was always off, and when I finally did come around to realizing how deeply I really did care for him, his heart had attached elsewhere. Nonetheless, he is still one of the most influential people in my life. He changed me for the better, subtly introducing me to the idea that there is no shame in vulnerability.

Since my big plans for my life included graduating college, traveling the world, having a lover in every port, and dying in my 20s, I never really thought that marriage would be my thing. Because every day beyond 21 for me was an excruciating reminder that I had one less day to live, my mind was not ready for permanence. It was only ready for experiences. I needed to drink of as many experiences as possible, in as short a time as possible. I never thought beyond increments of five years.

Somewhere around my 23rd birthday I met another influential man. He also was someone I could never see myself dating, someone I did not like initially, yet, somehow he grew on me. He, too, had a larger than life desire to experience the world. When I shared my illness with him, he became determined to make sure that I had everything a person could want before I reached 30. He had the money to do it, he lived the lifestyle to do it, and he absolutely accomplished it. He offered me the world on a silver platter and I readily took it.

Just shy of my 24th birthday, I agreed to commit the rest of my life to him in marriage. I was still very well armored, I still had no clue on how to deeply love someone, and I was certain I had only, at most, five years left to live. I was, clearly, not emotionally ready to marry, but I convinced myself otherwise, and married him anyway. When I reached 29 and was still very much alive with no chance of dying anytime soon, my world crashed in. Although he was the most experience-driven person I had ever met, and his lifestyle fit perfectly with mine, I found myself consumed with emptiness. I realized that I had made a very logically minded decision about something that should have been all about the heart. I was living with a very good friend whom I did not love. It was a hard realization and a hard break, but I had no choice but to be honest with him. For the first time in my life, I had to question the reliability of the 5-year-plan.

> "In the past six years I have completely peeled away the armor and have opened myself up to the risks of really being in love."

My 30s were challenging because my health was more challenging. The illness that had once crippled me more in my mind had now made its way into my body. I fell madly in love for the first time in my life. It was a weak in the knees, chemically charged kind of love that turned my world upside down. I thought I had truly found the love of my life. I found him at the wrong place and the wrong time, but I knew that my life couldn't be complete without him. I was certain that we would marry, and maybe even have children, and even more amazingly, that I might grow old with him. But it just didn't work out that way.

We were deeply in love and committed to each other for over a dozen years, we cohabitated for ten, and we even got engaged somewhere along the way, but I don't think his heart was ever really into marriage. And if my illness played a role in the eventual demise of our relationship, it would be because, somewhere along the way, my mind pivoted from an emotionally detached young girl, to an emotionally needy woman. The picture I had in my mind of a partner in "sickness and in health" was not my reality. There were other priorities for him, and I was alone most of the time. So I once again had to admit that I had been wrong, this time chasing great chemistry at the expense of compatibility. It was a disappointing end, heartbreaking for both of us; but, again, tremendously successful in confirming my ability to chip away at the armor and deeply love.

In hindsight I would have to say that my 20s were about frantically acquiring experiences and material things, and my 30s were about physical and emotional closeness with someone. My 40s are proving to be a decade of enlightenment and fulfillment.

In the past six years I have completely peeled away the armor and have opened myself up to the risks of really being in love. It was a long, long journey. Ironically, just as the armor came down, someone entered my life and rocked my heart and my world, and again, left me weak in the knees. I was certain that I wanted him in my future, but, unfortunately, he was only interested in the present.

Continued on page 23

A Path Worth Following

By Laura Tillman

I have no sage advice on dating or becoming engaged or going through the initial years of marriage while dealing with CF. That's simply because I had been married for over 19 years when I was diagnosed with cystic fibrosis. My husband, Lew, and I had been through the trials and tribulations of many of the "firsts" that come with relationships. We had accepted each other's faults and decided that we could live together, warts and all.

We had learned to handle each other's families and all that having in-laws entails. We had weathered the deaths of my parents and brother, as well as that of our beloved, furry, four-legged son, Sam. We had survived the many physical injuries as well as the long recuperation period from a major auto accident (that was not our fault!). We'd endured threatened job losses which never materialized; we managed not to kill each other through two moves. And we persevered through numerous other "firsts" that would fill pages. We were able to do so not only through love, but through friendship, respect, commitment, compromise, forgiveness, humor, and "it's just not worth it!". We quickly found out that romance, alone, doesn't help weather the storms and that some things are just not worth getting all worked up about. Our philosophy evolved: we learned to "just deal with it", whatever "it" might be.

But then came the diagnosis. This was different as there was no end in sight, other than death. The injuries from the auto accident healed, as did the pain of loss. Arguments and misunderstandings ended - when I no longer held a grudge! There was always some point of finality and getting on with our lives. But cystic fibrosis was a specter that would hover over our heads on a daily basis. There was no escaping it; vacations, time with friends, partaking in the activities we enjoyed, even having another fur-kid around, didn't take our minds off of it. It didn't matter if I did everything humanly possible to deal with this disease; it was, and would always, be hanging around. There was absolutely no escaping CF!!

> "Lew showed his love and support by taking an active role in all that was required of me by this disease."

I was horribly bothered by the fact that, at that point in time, Lew would be the one to have to help me with physiotherapy. It was bad enough that I had to spend hours of my day on treatments, but to need Lew to spend a portion of his waking hours having to do percussion on me seemed so unfair. As we left the hospital after he was taught how to "beat" me, I said - no, actually I wailed, "What are we going to do?" He, of course, was highly philosophical about it all. "We'll just deal with it. What else can we do?" And that, indeed, is what we did.

We developed a routine that had our lives revolving around my treatment schedule, and we adapted to that routine, hard as it was to do so. My husband, who never questioned any medical personnel and can't stomach watching "ER", learned to ask questions, learned medical jargon pertaining to CF, and learned how to access my port and help me change dressings. He showed his love and support by taking an active role in all that was required of me by this disease.

Oh, it wasn't easy. There were plenty of times he probably wished I wasn't so stubborn and hotheaded, or that I would just disappear! And there were numerous times I wished that he would stop nagging me about things. We both felt the pressure of this diagnosis, but after many months of adjusting to our new lifestyle, we reached an understanding of where each of us was coming from. Our frustrations were due to worry and concern. He worried about my health and the possibility of my death. I worried more about my job and what Lew would do if I did die. I mean, how could he ever carry on without me!

The control freak in me was more concerned about maintaining things as I wanted them to be, rather than as they needed to be. So, we both realized that we had to accept how we each coped with CF, just as we had done and continue to do, with other areas of life that we have to deal with! It was harder with CF, though, since it occupied so much of our time and energy, took up so much space in our home, and caused aggravations that were beyond our control - like insurance issues, billing mistakes, and various and sundry other blips!

Continued on page 30

For my Wife

Morning Comes
My eyes open
I feel the warmth of your body
I breathe in
No movement yet
I watch oh so silently
I can feel your presence
I know, you know
I'm watching you
Movement
Your hand slowly moves upward
I watch Your hand slowly reaches for air
Searching
I lie still
Waiting
Anticipation overwhelms me
Movement
Morning sunlight shines off your hand
My body feels my blood
Still waiting
The warmth of your hand
so close
Movement
The fine hairs on my body tingle
Then The touch
The transfer of knowing love
Complete
No words
No sound
Movement
With one touch
Acknowledgement
You know
In my soul
You will always know
I love you
In my mind, I will always find the time for you
In my heart, we will never be apart!
Movement
You roll over
No words
No sounds
Movement
Says it all
Eyes touch.

– P. Howell

"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...

ISA STENZEL BYRNES IN THE VIRGIN ISLANDS.

JONATHAN QUIGLEY & JESSICA SMITH ON THEIR WEDDING DAY IN ANNAPOLIS, MD.

LISA MARTINI AND KURT ROBINSON AFTER ONE OF LISA'S VOLLEYBALL MATCHES.

PAUL AND KATHY RUSSELL..

KRISTI AND PAUL FELD AT THE TRANSPLANT GAMES IN PITTSBURGH, PA, IN 2008.

ANDREA EISENMAN WITH HER DOG ERNIE.

CELEBRATING HER 10-YEAR ANNIVERSARY OF HER BILATERAL LUNG TRANSPLANT, MICHELLE COMPTON SCRUTINIZES HER LIKENESS ON A PIECE OF CAKE.

LEW AND LAURA TILLMAN.

The Onset of Winter

By Pammie Post

The cold winds have started to blow here in Connecticut, making temperatures feel much colder than normal. The winter frostbiting at our Yacht Club has been canceled for the past month, due to gusts above 18 knots. The small dinghies will capsize too easily in this type of weather.

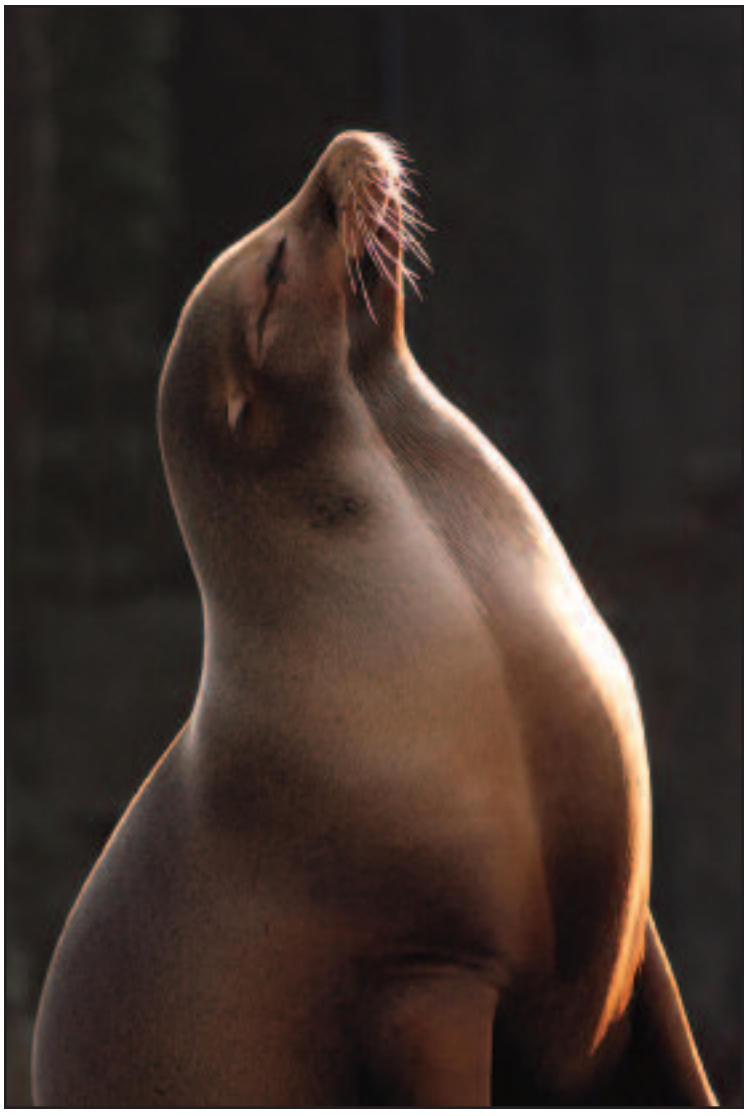
Last year we had a mild winter, in comparison to others, with very little snow. This created a huge disappointment for children who anticipated a snow day from school. I too was a bit disappointed not to be able to capture the wintery scenes close to home. There is nothing quite like going out early with the camera after a huge snowfall. A great sense of peace surrounds everything.

"Winter in Damascotta", Maine

It's tradition that every winter, a great friend and I travel to Maine in early February to celebrate Lin's, (my older sister) birthday. Are we nuts, yes! It is always freezing cold, not what we are used to at all in the southern climes, (CT and NY).

Back in 2007, Gladys and I chose to visit a few of our favorite spots about 1½ hours east of Freeport. Life is much different in the winter months. There are no busloads of tourists; no Winnebago's on Route 1, no open lobster roll stands along the sides of the road. The towns, too, seemed somewhat abandoned. In Boothbay Harbor, you can get a free cup of coffee if it is snowing outside. Too bad it wasn't snowing

We ventured out on one of the coldest bone-chilling days. Midday, temps were hovering at 14°F., but with wind chill, it felt like 3°. That day, the lobster men kept



their boats on the moorings. I was still determined to photograph. Gladys would stay in the car as I set out with the camera until my face and hands were numb.

As we were driving back to Freeport through Damascotta, the winter sun was setting. As I looked back on this lovely town, a warm glow enveloped it, very picturesque. Quickly, we had to find a location to capture the fast fading light. Gladys ventured down a small road across from the town. No trespassing signs were posted on private driveways along the river, even in front of the bank's parking lot. The bank was the best bet and it was closed. The snow was a foot deep capped with an icy, crusty layer. With camera and tripod in hand, my big boots broke through the crust with each step, as I wandered close to the river. Before mounting the camera to the tripod, I walked around to find the best point of view, though I was freezing and the light was changing quickly. My camera's viewfinder quickly fogged up with my warm breath as I was trying to frame and focus the shot. The grass in front of the river was included to add interest, depth, and to keep the horizon out of the middle of the photo.

Camera info: February 8, 2007 at 4:07pm. Nikon D80 1/160 seconds, F16, ISO 250, white balance auto, with a Nikkor 18-135 mm at 48mm.

"Driving Through the Adirondacks", between Lake Placid and Keene, NY

Change is good. This year my husband, Bill, and I spent Thanksgiving in Lake Placid, just the two of us. We drove up on Thursday arriving at the hotel in time for a wonderful turkey dinner, no cooking and no clean up. The place was packed with families. The next day, Whiteface Mountain had their grand season opening.

Snow was predicted for Friday and Saturday and boy did it snow. The visibility was limited. We had planned to drive up the Veterans Memorial Highway to the top of Whiteface Mountain to catch a fantastic panoramic view of the Adirondacks. Again, the road was closed, due to poor weather conditions. Fog had prevented us in September 2007. Photography is not limited to good weather. But this time it wasn't worth going out with the camera. The wind blew the snow in every direction. There wasn't a way to keep the snow off the lens filter, even with my back to the wind.

To protect my Nikon D90 with an 18-200mm telephoto in adverse conditions, I put my camera inside a 2½ gallon Hefty OneZip bag. It does work and is less bulky, less expensive than some other fancy gear protectors with zippers and Velcro. Cut a tight lens-hood-size hole at angle in the far corner of the bag. Push the lens hood through the hole. With painter's tape, tape the bag to the hood. Make sure it is taped well and that there is no tape showing beyond the hood so you won't see the tape in your photos. Insert the camera and attach it to the lens hood. Zip up the back. The 2½ gallon bag is made with thicker plastic than the normal 1 gallon bags are.

The drive to Lake Placid and back towards I-87 on Route 73 is just beautiful. The road winds through the mountains alongside the Au Sable River, a perfect occasion to take out the camera and wait for the right moment. Because we were traveling around 35mph, a fast shutter speed was necessary to avoid blurring. There was no room to pan from the passenger seat, looking through the windshield at a 45 degree angle, without catching the mirror or Bill. The opportunity arose when I saw the mountain tops in the distant dressed in light.

This photo reminds me of a medical journey or life's journey. We sail along comfortably and then unexpectedtly, we come around a sharp corner and — bang. The road now has yellow danger signs along its path, "Fallen Rock Zone" or possible wicked infection, a new diagnosis. A car is fast approaching in our lane. Quick, now is the time to switch gears, to be alert and proactive. We are nourished by nature's beauty along the way. Yet, in times like these, I always look for the light and move toward it with positive energy and thoughts of being well again, no matter how tough the journey might become, no matter the diagnosis. Think miracles.

Camera info: Nov. 29, 2008 at 12:50pm. Nikon D90 at 1/1250 seconds, F 9, ISO 500, White Balance Auto and with a Nikkor 18-200mm VR lens at 75mm

"Basking", (Sea lion), Central Park Zoo, NYC

A person does not have to travel to distant lands in order to photograph animals. Yes, it would be more exotic and fun with different species, sceneries and environments, but there are plenty of resources close to home. The local zoos offer many photographic possibilities.

Members of my family went to NYC after Christmas in 2007. A trip to the Central Park Zoo is always a must-see with children. And guess what? There was an adorable baby snow monkey at the Zoo! That did it. I had to see this little creature.

On January 7, 2008, Gladys and I took off to see the snow monkeys. The day was overcast and yet a balmy 50 degrees, very warm for winter. There he was, this tiny little monkey covered with brown fur on the back, arms and legs with white on the front and a very red face, just like all the other monkeys. We watched him hover with his Mum, nursing and following her around. Even with a 70-300mm telephoto, I couldn't get a good shot. The two of

Continued on page 29

Thanks To Scruffy and Ernie

By Andrea Eisenman

He: I have been to Africa with the Peace Corps, lived in France for a while, grew up in Long Island but moved with my family to Arizona and went to college out there. Where did you grow up?
Me: I grew up in this neighborhood.
He: So you are a native New Yorker.
Me: Yup.
He: So, have you traveled much?
Me: Well, I have been to Italy twice and the Caribbean as well as most states. But traveling for me was not so easy. You see, I have cystic fibrosis and was sick a large part of my life.
He: People die from that, don't they?
Me: Yes. But I also had a double lung transplant six or so years ago. I am much healthier now.

There you have it, full disclosure to someone I met in the dog run — someone, who now is my recently wedded husband, Steve Downey.

For me, telling someone I am dating, or about to date, about having CF is so nerve-wracking. On top of that, having a lung transplant is a lot to drop on someone who knows nothing of either. Will they understand, will they want to be with me, will they be scared off? All that goes through my mind when I feel it should be disclosed.

I first met Steve in the local dog run. We met cute, as they say. We both had gotten dogs about the same time as each other. He had just started his own company and worked from home. And for me, I missed having a dog in the city and felt it would get me out and about in the fresh air.

My dog, Ernie, was a puppy when I got him so I had to wait for a while to take him to the dog run. Steve adopted a 6-month-old pup that he named Scruffy. Once Ernie and Scruffy met, they liked to play with each other, with a stick between them, each pulling for dear life. During those struggles I started to talk to Steve and others in the run. I made many friends there. It was a great social experience for Ernie and me. He got his exercise and I got a new social circle of friends.

As Steve and I got to know each other, with no expectations, I started to notice that he seemed interested in me. But no one in the run really knew I had CF or a transplant. It really never came up. I would start talking about Ernie or someone else's dog and the next thing we knew; we were discussing books, movies, politics, etc. But as I started to notice Steve's interest, I also started to be more interested in him. And he was interesting. He had been very independent and, being in the Peace Corps, he had many stories and incidents to recall. He had also lived in Arizona and raised horses. Steve also had a dry wit and made me laugh.

So, over-thinking things, I figured, I will just tell him about me and my "health issues" while we are still friends. I was not really sure we would ever be more, but it gave me practice to drop "the bomb." So ensued our interaction above. It was funny as I had never heard his reaction before, but he did not seem phased by it. Although, I am not sure how much he understood about any of it, either. I figured it would be fodder for more discussion at another point.

I thought that if he ignored me after that conversation, then I never had to invest too much and be disappointed later on. At the time I met him, I was through with "L'amour". I had been in an on-and-off-relationship for over four years and was done. I just did not want to make the effort anymore, but it was easy with Steve.

As it turned out, after our conversation, he was still giving me signals, but I could tell something was bothering him. I didn't know how old he was, but I thought that he might assume I was too young for him.

ERNIE BIRNBAUM, ANDREA EISENMAN, STEVE DOWNEY AND SCRUFFY O'DUFFY AT HOME.

After a few weeks, he asked me what my favorite food was and I responded, Japanese. He said, "You mean, like sushi?" And I said I loved sushi. He indicated that he had never had it and I asked him if he wanted to try some at some point. (This he later related to me as, "This young chicky was asking me out?") I know, it was bold, but I figure life is too short to always wonder "What if?".

So, we went out on a date for sushi. Not his favorite food. But we had a great time and when we went to a dessert place near the Japanese restaurant, he asked me my age. He seemed relieved to find out that I was only 8 years his junior.

We dated, took our dogs for walks, and played tennis. He met my family and friends. I met some of his family that lived in New York. I told him about CF and my life with it leading up to my transplant. It is hard for my "new friends", meaning post-transplant pals, to fully comprehend my life before transplant. Because, when you see me now, I am almost overweight, never cough and can do almost everything anyone else can do. But I told him about how sick I was and how lucky I was to get the transplant when I did. And about what my life was like, waiting for that call to come to save me from dying at 35-years-of-age. He took it all in stride, and when he didn't know or understand something, he asked.

He moved in with me after about six months of dating. We had discussed marriage but nothing serious. I had to let him know that I could not have biological children, another anxiety-invoking conversation for me. It turned out that he didn't particularly want kids anyway. He had many nephews and a niece and he loved them. We were open to adopting but neither of us felt a strong desire to bring up kids at our ages. After nine months of dating, he proposed.

His proposing was a total surprise to me. We enjoyed being with each other and I knew he had had long-term relationships, as had I, without ever being married before. It was scary territory for both of us. I accepted his proposal and we then planned our wedding. It was very stressful—the planning, the gearing up for a big wedding, and in the middle of it, I had to be hospitalized.

It was my first hospitalization since I had met Steve. I had wondered how he would handle it and whether it would scare him. He rolled with it. My hospitalization happened to fall on the day before I would have left for the transplant games. I had decided not to go, a few days earlier, as I had several bouts of hyponatremia—low-salt—from sweating too much while playing tennis. I was so disappointed, as I had trained a lot and looked forward to competing. My electrolytes got so low that I had panic attacks and lost about 8 pounds, aside from other issues like a fever, nausea, etc.

Everyone assumed it was wedding jitters but I knew it wasn't. I knew that Steve was the one, because I felt so happy and calm with him. Even my friends thought I had never looked better since meeting him. Eventually, I normalized and the wedding went on. It was a great ceremony and party. I look back on it as a celebration and appreciation of life.

While marriage was never my goal, I longed to be able to find someone with whom I could share the rest of my life. I found that in Steve. We are happily married now for three months. The road ahead is unknown and may be rocky. But having someone to share that road with was worth the 43 years of my life I waited to find Steve (and Scruffy and Ernie). ▲

Andrea is 44 and has CF. She is a Director of USACFA and is the Executive Editor/Webmaster. Her contact information is on page 2.

RADLER *continued from page 15*

Ultimately, my illness proved to be too much for him and he rejected me because of it. Of all the many things he had ever said to me, "If not for your illness, I could love you," were the words that continue to resonate with me. I had finally come full circle. He proved to me that childhood fears sometimes do come to fruition. But despite the intense heartbreak, I did not pile on the armor again. I lived through it, learned from it, forgave him for his fears and his armor, and moved on to where I am today.

I am now 46 years old. Dare I say I'm in love again? I have been married for a year and a half to a man who personifies goodness, honesty, integrity and faith. He has a tremendous sense of humor about me and understands through his own journey that we all have the potential to fulfill and to disappoint. We are working hard at this relationship as a team, and there is no one I would rather have on my team. In the past two-and-a-half years that I've known him, he has seen me through more health-related problems than most will encounter in two-and-a-half decades. I think he and I would both agree that acquaintanceship in the world of CF is much easier than commitment in the world of CF. The faint of heart need not apply. But a lifetime of mere acquaintanceship would have left me empty and yearning for something deeper.

Twenty five years ago the "lover in every port" plan seemed absolutely brilliant, but now, I wouldn't trade my life for the world. My husband's commitment to me is the most generous gift anyone has ever given me, and I consider myself blessed to be able to enjoy this beautiful leg of my unconventional journey with him. ▲

Debra is 46 and has CF. She and her husband, Adrian Gulinski, live in Roselle, IL.

The One

By Kurt Robinson

I was so excited to write this article that I turned on my computer, opened up Microsoft Word, started to type and...I kept erasing what I wrote. I probably spent a good ten minutes typing and erasing, then I thought to myself "Why do I keep erasing what I just typed?" After thinking about it for a few minutes, I realized it is because what I am about to write comes straight from the heart. I wanted to be sure that what I wrote was how I truly felt and to be sure that I didn't leave out anything relevant or worth mentioning. An article that I thought would be quick and easy to whip out turned into anything but that. But that's how an article like this should be.

At a recent USACFA conference call with our Board, many of us expressed excitement over this issue's Focus topic (Love, Dating, and Marriage). This has been a Focus topic that I have been looking forward to for months. It's a chance for me to brag about my significant other and I plan to do just that. But it's also a chance for me to share just how I felt in certain situations regarding relationships.

I have been fortunate to be in two great relationships. I say two, because the first one didn't work out, but I can say that we are still the best of friends. I am not someone who can attest to what it's like to jump around from relationship to relationship because that's not me, it's never been me, and it never will be me. Quite honestly, in a relationship, having a partner who has cystic fibrosis isn't for everyone either.

Whether those of us with CF want to admit it, most of us require more "work" to keep our parts running than most non-CFers. CF is something that is constantly on my mind. I have constant reminders: coughing, medication, treatments, medical bills, doctor's visits, etc. It is also a cause that I deeply want to find a cure for, which is why I stay very involved in raising money for cystic fibrosis. Consequently, I realized after my first relationship ended that whoever I entered a new relationship with had to be 100% okay with me having CF. Not 98% or 99%, but 100%. It may sound selfish, but I knew that's the only way the relationship would stand a chance of getting off the ground and, hopefully, working out.

I have written about the love of my life, Lisa, in the previous two issues. We haven't even been together for a year, but you wouldn't know it. Two years ago we didn't even know each other. When I met her she was not much more to me than a good college volleyball player who played for my alma mater (sorry babe!). However, earlier this year things changed and we began to have a strong attraction for one another in a very short period of time. We spent hours talking on the phone, online, exchanging e-mails and, finally, seeing each other in person. So in that short period of time we got to know a lot about each other.

I had hinted about CF, but never directly stated to her "I have cystic fibrosis". I have always been very open about having cystic fibrosis, even speaking at numerous CF Foundation fundraisers over the years, so telling my story about CF to someone wasn't anything new. But how would I tell this person, whom I already cared a tremendous amount for, that I have cystic fibrosis? Just like I did everyone else. I figured, why should I change who I am? She wants to get to know the real me; well, this is the real me. She said she thought that may have been the case after all of our conversations, but she didn't want to come out and ask. Like I said above, I've always been open about CF, so I told her if she had any questions to just ask. Maybe it wasn't the best way to say it, but it was the easiest. I say that because I could see that she had a lot of questions to ask, but didn't know where to start. Sometimes it's just easier if you say, "Would you like to know more about it?" Don't be upset or hurt if they reply with something along the lines of "No, thank you" or "Not now".

I've always heard people say that nobody's perfect. To me, Lisa is perfect. She's why I get up every day and do my treatments, take my medications, try my best to stay healthy, and look forward to the day ahead of me. She is who I think about 24/7, who I dream about, and who I care about. Don't get me wrong, there are *plenty* of other people in my life who mean a tremendous amount to me, but Lisa is numero uno.

Even since the first few weeks in our relationship, she has taken an active role in my daily CF routine. She reminds me to do my treatments, take my medications, go exercise, get plenty of rest, and stay healthy. Fattening me up with yummy food is also a favorite for her! She wants to know what all of my medications do, why I take them, how many of each pill I take, and at what time of the day I take them. She wants to be my workout partner. She wants me to be healthy and live a long life. She knows that life will include her. I know she does all of this not because

she has to, but because she wants to, and I can't tell you how much I love her for that.

Speaking of love, I never knew I could love someone so much, that I could love her more every single day, or that I could fall in love so fast. But I have and the feeling is more than I could ever put into words. We hadn't even been together for a month when we told each other those three special words. She keeps me going every single day. She understands when I'm not feeling well and tells me when I should get in touch with my doctor. Cystic fibrosis does not consume my life, nor does it consume hers, but it is there and, for now, it isn't going away. I won't ever let it consume our lives, either. We have way too many plans for the future and none of those include CF. However, if something CF-related does pop up, we'll adjust, deal with it, and continue to live the happy life we share together.

To say that Lisa is "the one" couldn't be more of an understatement. I had always heard the saying "when you know she's the one, you know", and believe me, I know! She is an outstanding volleyball player, an honors student, a hard worker and, above all that, an amazingly sweet and caring person. My niece, Emry, gets more excited to see Lisa than she does me and I couldn't be happier when Emry runs up to Lisa for a big hug. She will be a wonderful aunt, a fantastic daughter-in-law, terrific sister-in-law, and best of all, she will be my wife. I look forward to watching her walk down the aisle and sharing our wedding day with our family and friends. Most of all, I look forward to spending the rest of my life with her. ▲

Happy Birthday Lisa. I love you!
~Kurt

Kurt is 25 and has CF. He is a Director of USACFA. His contact information is on page 2.

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WELLNESS

The Key To Happiness???

By Julie Desch, MD

In this issue, where the focus is on "love, dating and marriage," I want to discuss *connection*, and how it is essential for positive well-being.

I am in the process of writing a book (it will be a long process), which will describe the use of evidence-based findings from the emerging field of positive psychology in living successfully with a chronic disease. I thought it best to come up with a cute tool (read: gimmick) that will hopefully lighten up, and perhaps make more enjoyable, an otherwise rather dry subject.

The idea came to me at 12:30 am one night when I could not sleep. I had been chewing on an idea for a membership website which would be a place where people with chronic illness could hang out to get support, ideas, coaching, and other products that would help them to live as healthfully as possible. While on vacation with me, a friend suggested jokingly that a good name for such a site might be "notdeadyet.com." Of course, everyone laughed at the absurdity of such a name but, apparently, it stuck in my subconscious mind.

So that night the idea hit me like a gale force wind. **Notdeadyet** is not a website name…for so many reasons.

But, perhaps, it is an acronym for the book! I sat up immediately and took out my journal. Each letter in the acronym began a phrase that summed up what I have learned (through living with CF, being a physician, coaching others, and studying positive psychology) about being HAPPY while being SICK.

The weird thing was…I didn't even really think. These phrases just sort of came to me…quickly. I had to write them immediately because I was afraid I would forget them (there is a precedent for this, trust me).

It was clear – Sick and Happy was the title (or at least the main part of it), and each of the chapters was going to cover one of the phrases, delineated by the acronym **N O T D E A D Y E T.**

And here they are… drum roll please:

Notice what your body still can do, and take pleasure and pride in those things.

Only eat, drink, say and think healthy food, drink, words, and thoughts (i.e. cut out the crap).

Take complete control and responsibility for everything you can.

Do what you love!

Engage fully in life.

Accept what you cannot change without becoming a victim.

Discover your strengths and use them every day.

You are not alone – *connect* with others and give and receive support.

Envision the meaning of, and opportunities found within, your illness.

Thank everyone for everything.

More to follow on this (I write a blog at www.sickandhappy,com where I play with this idea).

JULIE DESCH, MD

Connection is the focus for now. A very interesting study was done in 2002, looking at what made college kids happy (1). Now, I know what you are thinking. All college kids are happy! Why wouldn't they be? They have no responsibility. They get to wake up when they want. They are free from parental control for the first time in their lives. And then, there are the fraternity parties…

Not so, apparently. Using multiple assessments, 222 college kids were divided into groups that were "very happy," "average," and "very unhappy". Countless studies have, of course, been done on unhappy people with various psychopathologies, but this was the first to focus on very happy people. The conclusions were fascinating.

Several variables were assessed, including things like social relationships, personality and psychopathology, the perception of wealth, number of objective positive and negative events they had experienced, grade point average, physical attractiveness (rated by coders by looking at pictures), use of tobacco and alcohol, time spent sleeping, watching television, exercising and participating in religious activities. All of this data was collected over about 50 days by having the subjects do daily logs.

The researchers were looking for the key(s) to happiness…what variable(s), if any, would be either sufficient or necessary (or both) to put someone in the very happy group? The term sufficient in this case would mean that all people who had that variable were "very happy." Necessary would apply to a variable if virtually every person in the very happy group possessed the variable. Are you with me?

Now with that very simplified explanation of the study done, on with the results. Sadly, NONE of the variables evaluated were "sufficient". There is no magic key to happiness…at least, not in this study.

However, a few variables were found to be necessary conditions for high happiness…the one that this article is concerned with is that "*very happy people have rich and satisfying relationships and spend little time alone relative to average people*." It also helps to not be neurotic or have much psychopathology (i.e. depression), and to be an extrovert.

Bummer. So there is nothing magic to do or get that will, by itself, provide happiness. But, trying to manipulate the variables that are necessary to be happy is a good way to improve your odds, right? Of the four discovered (lack of neurosis, minimal psychopathology, extroversion, and rich social relationships), the easiest one to work on is the last.

Happiness does not appear to occur without rich social relationships.

So, don't be a recluse. Reading blogs and commenting in forums is fun, but is not sufficient to build rich personal relationships. What is necessary is to connect with others…in person. And this applies even more, I think, to people living with the stress and inconvenience of chronic illness.

When you don't feel well, it is very easy to hole up and not be social. I get it. You don't look your best. You don't feel your best. You don't have energy to be social. You don't want other people to think they need to help you. It's just easier to curl up with your dogs and watch Hardball!

1) Diener, E., Seligman, M., (2002). Very Happy People. Psychological Research, 13(1), 81-84.

But therein lies the problem. Hanging out alone keeps you mired in yourself. It becomes easy to feel sorry for yourself, jealous of others, and just generally pissed off that you don't feel great. And there is no one there to tell you differently! You get no other perspective.

The next question becomes, "How do I just start being social when I've never been before?"

It starts with calling someone. At first, maybe it will just be family members. Connecting more frequently with them is a great step in the right direction. Over time, you might be emboldened enough to call a friend to set up a date for coffee or lunch. Then, maybe you can make a goal to call a different friend once a week. Then…you get it. Small steps. But necessary ones! ▲

Julie is 48 and is a physician who has CF. You may send your CF-related medical questions to her at jdesch@usacfa.org.

Information from the Internet…

Compiled By Laura Tillman

This issue brings a potpourri of articles from the Internet

CFRD

Sex disparities in effects of cystic fibrosis-related diabetes on clinical outcomes: A matched study. RJ Miller, HD Tildesley, PG Wilcox, H Zhang, SH Kreisman. *Canadian Respiratory Journal*. September 2008, Volume 15 Issue 6: 291-294

Cystic fibrosis-related diabetes (CFRD) is an increasingly prevalent comorbidity factor for patients with cystic fibrosis (CF). CFRD has been associated with an accelerated decline in clinical parameters and an increased mortality rate. Patients with CFRD had higher rates of FEV_1 deterioration than nondiabetic patients with CF, and showed a trend toward increased mortality. The present study suggests that CFRD has a significant clinical impact and should be carefully considered when evaluating the status of CF patients.

http://tinyurl.com/a39kak

ANTIBIOTICS

Once-weekly azithromycin in cystic fibrosis with chronic *Pseudomonas aeruginosa* infection. Gratiana Steinkamp, Sabina Schmitt-Grohe, Gerd Döring, Doris Staab, Dietmar Pfründer, Gudrun Beck, Ralf Schubert and Stefan Zielen. Respiratory Medicine, Article in Press

Data on the effects of long-term treatment with azithromycin (AZM) on inflammatory markers in cystic fibrosis patients chronically infected with *Pseudomonas aeruginosa* are scarce. So far there is no pharmacokinetic and clinical data on once-weekly dosage of AZM in CF patients. In a randomised double-blind, placebo-controlled trial, patients received AZM or placebo 1 per week for 8 weeks. Once-weekly azithromycin ameliorated inflammatory reactions and improved quality of life. A decline of pulmonary function after cessation of IV antibiotics could not be prevented.

http://tinyurl.com/8gzdm3

Long-term, low-dose azithromycin

Continued on page 29

Voices from the Roundtable

Hard Knocks

By Joni Murphy

Life can be very hard, sometimes when you least expect it, and I believe it can get even harder when you don't address it quickly. Life has spiraled up and down and all around for me. Maybe CF and diabetes caused it, but I think not.

I'm almost 48 years young and they told my parents I would live for only seven or eight years. I always would sneak and listen to these interns grill my mom (I was supposed to be waiting in the play area), and my mom would tell them how our family didn't have the money or means for the best possible care I should be getting. That doesn't compute, for interns. I grew up feeling guilty for being such a financial burden on my family, and to this day I still do. I ruined my first marriage and moved far away to a very hard life that I was not ready for, at all. I learned quickly. To survive a harsh and cold environment you become desperate to hold onto your sanity.

I came back home angry (more so than when I left) and had to start another life all over again. I went through a depressed crying spell for almost three years and I attempted suicide twice. Both times I should have died. No one can explain medically how I didn't die, except that it is for a reason that I'm alive and still breathing. Since getting professional help, now going on 13 years, I have made mistakes that hurt the people I love; but I can look them in the eyes and humbly apologize and really mean it and it doesn't seem so hard, just embarrassing.

My mom passed away two years ago from emphysema and here I have CF, go figure. Her cigarettes finally got the best of her. I miss her dearly and when I come to a challenge in life, I ask myself what she would say to me. Her hillbilly Hazard, Kentucky ways would come out and an ass-ripping I'd get. 98% of the time she would be right and I'd fail. So I don't know if I'm stupid or just experiencing "hard knocks".

Even at my age and experiences in life, the world is big and cruel and mean. But we, as American's, survive and persevere over these obstacles every day. Look at this stupid war and our economy, no cures of diseases, drugs and guns on the streets, kids killing one another. All these are "life", not just hard knocks; like a divorce or DWI, which can be dealt with rationally.

I'm single, no kids and carry a lot of baggage. But I'm grateful for waking up every day and just doing whatever. I go to doctors a lot and am on SSI and disability and, thanks to my sister and brother-in-law, I have a nice home to live in. I just lost a kitty-cat of 12 years last weekend. I cried for four days, but it is on my list of "hard knocks", also.

If there is anyone out there in the CF world who has similar beliefs, please feel free to write me at: 296 N Meridian St, Marengo, IN 47140. Have a good day and be thankful for your life, because it means something to someone, whether you know it or not.

CONVERSATION CORNER

I just wanted to add to your roundtable ideas on what equipment makes life easier. I put my nebulizer on remote control so that I can I have the machine behind the couch. I always hated the sound of it running, if I stop in the middle of a treatment. With the remote the machine no longer had to be in reach all the time.

Also, a 20-foot-hose on the machine gave me more options of places to sit while doing the nebulizer. The couch, my stationary bike or the computer all now are options.

I also have a tiny PARI Trek nebulizer machine for vacations and overnight trips. The machine and all the paraphernalia take up about as much room as a pair of shoes. I could not stand hauling the regular machine on vacations. With reduced luggage allowance these days I am ever more grateful for the small machine.

I took the PARI to the United Kingdom for vacation and was able to run it using an adapter for the cigarette lighter of our rental car.

Thank you for all your effort. You are my best source of CF information.

Sincerely,
Darleen Boynton
Ann Arbor, MI

treatment reduces the incidence but increases macrolide resistance in *Staphylococcus aureus* in Danish CF patients. C.R. Hansen, T. Pressler, N. Hoiby and H.K. Johansen. Journal of Cystic Fibrosis. Article in Press

Long-term, low-dose treatment with azithromycin in CF patients leads to reduced prevalence of *S. aureus*, *S. pneumoniae*, and *H. influenzae*, but increased macrolide resistance in *S. aureus*. Reduction in the prevalence of *S. aureus* will make increasing macrolide resistance clinically insignificant in these patients.

http://tinyurl.com/8d5sqw

A retrospective analysis of biofilm antibiotic susceptibility testing: A better predictor of clinical response in cystic fibrosis exacerbations. Tara Keays, Wendy Ferris, Katherine L. Vandemheen, Francis Chan, Sau-Wai Yeung, Thien-Fah Mah, Karam Ramotar, Raphael Saginur and Shawn D. Aaron. Journal of Cystic Fibrosis. Article in Press

Bacteria grow as biofilms within CF airways. However, antibiotic susceptibility testing is routinely performed on planktonically-growing bacteria. This study assessed whether CF patients infected with multiresistant organisms had improved clinical outcomes if given antibiotics that inhibited their biofilm-grown bacteria. Most patients with CF exacerbations do not receive antibiotics that inhibit all biofilm-grown bacteria from their sputum at exacerbation. Patients treated with biofilm-effective therapy seemed to have improved clinical outcomes.

http://tinyurl.com/lcwal

Cystic fibrosis, aminoglycoside treatment and acute renal failure: the not so gentle micin. Detlef Bockenhauer, Martin J. Hug and Robert Kleta. Pediatric Nephrology. Published online

Aminoglycosides have a wide spectrum of gram-negative anti-bacterial activities and are available at low cost, which makes them commonly used drugs, especially for patients with cystic fibrosis (CF), who often suffer from chronic lung infections from *Pseudomonas aeruginosa*. Unfortunately, this treatment seems to have resulted in an increased incidence of acute renal failure (ARF) in patients with CF. A recent case–control study investigated risk factors for ARF in CF patients and suggested intravenous use of gentamicin as the prime culprit. Moreover, in most cases, at least one other risk factor, such as CF-related diabetes, pre-existing renal failure, dehydration or concurrent use of other nephrotoxic drugs, was present. We comment on the renal handling of aminoglycosides and the possible mechanisms of toxicity, as well as strategies for risk minimisation.

http://www.springerlink.com/content/r8498408888202v2/

BACTERIA

MRSA and Pulmonary Function in CF. Neil M. Ampel, MD. Am J Respir Crit Care Med. 2008 Oct 15;178:814

In a large cohort analysis, pulmonary function declined 43% faster in CF patients with persistent MRSA respiratory infections than in those with no MRSA infections.

http://infectious-diseases.jwatch.org/cgi/content/full/2008/1022/4?q=topic_respinf

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The impact of incident methicillin resistant *Staphylococcus aureus* detection on pulmonary function in cystic fibrosis. Gregory S. Sawicki, MD, MPH, Lawrence Rasouliyan, MPH, David J. Pasta, MS, Warren E. Regelmann, MD, Jeffrey S. Wagener, MD, David A. Waltz, MD, Clement L. Ren, MD , for the Investigators and Coordinators of the Epidemiologic Study of Cystic Fibrosis. Pediatric Pulmonology. Published online: 7 Oct 2008

Although MRSA in CF was a marker for more aggressive therapy and may reflect increased disease severity, incident MRSA detection was not

Continued on page 30

them were mainly staying out of site, close to the bushes a long way from the rail where we were standing, not venturing on the rocks or down by the water. The background was cluttered. So, it was off to see Gus and Ida, the polar bears and other outdoor animals. Post transplant, I refrain from venturing into indoor aviaries or other potentially harmful exhibits, due to risk of infection.

As Gladys and I were leaving, the sun started to pop through the clouds. Once again, we revisited the Sea Lion pool, located smack in the middle of the zoo, a huge attraction for school kids and the like. Timing was excellent! The three adult sea lions (all female) had just been fed so the crowds had dissipated; ergo we had front row viewing. The sight of one sea lion sitting proudly on a rock, "basking" like a human, immediately caught my eye. The side light was phenomenal, outlining her sleek fur but not so sleek body.

I walked around the pool to get the best camera vantage point for the light on the sea lion, noting any background distraction, which was not facing any other exhibit. She moved her head around at times to let us know she wasn't a statue. Because my tripod was at home, the pool's surrounding rail was perfect for resting the camera. I had recently read a photo tip about changing the camera's white balance to a shade setting; even if there is sun, it will add more warmth to the photo. This seemed like a good opportunity to try it. The sea lion was an A+ model!

Camera info: January 7, 2008 at 12:50pm. Nikon D80 at 1/400 seconds to stop all movement, F6.3, to blur the background, ISO 500, white balance shade, with Nikkor telephoto 70-300mm. I did darken the background a little in Photoshop CS2.

Until next time, happy shooting and always look for the light. ▲

Pammie is 55 and has CF. She and Bill live in New Canaan, CT.

CONVERSATION CORNER

It is a great honor to address the readers of CF Roundtable, a newsletter I have so much respect for.

My name is Michelle Savta and I'm from Pittsburgh PA. I have a brother with cystic fibrosis. I'm an advocate & help spread awareness about CF online (something I also do for a living but for very different causes.) I believe in the power of people helping people.

I would like to introduce to you the CF Online Support Group at <www.mdjunction.com/cystic-fibrosis>.

The Support Group is a new addition to MDJunction, which is a FREE center for online support groups. They have more than 600 groups who serve thousands of people every day and help them better their lives.

We hope that the group will serve as a meeting place, a home for people who want to share their feelings or information, ask questions and just be around people who are dealing with the same challenges as they are. Those people understand you best.

It would be great if you drop by and introduce yourself to the group.

I'll be waiting,
Michelle Savta
Pittsburgh, PA

TILLMAN *continued from page 16*

Having CF didn't exactly enhance romance, but it did strengthen our relationship more than ever. Committed as we were to each other, this just brought us closer. Although we've always been aware that someday we would have to face the death of a partner, CF made "someday" seem more imminent. And that meant our time together was so much more precious. And so, we added another element to the list that keeps us together: appreciation. Not only do we value each other more than ever, but we also appreciate the little things in life that were always taken for granted. It also helps that we harbor the same values and sense of humor.

That sense of humor has been the glue that keeps us sane. I started this piece by saying that I have no words of wisdom regarding relationships when one has CF. However, I will leave you with the most important piece of advice that Lew puts to use, on many occasions. Always remember these words in the heat of a disagreement, "Would you rather be right, or would you rather be happy?" ▲

Laura is 61 and has CF. She is a Director of USACFA and is the Secretary. Her contact information is on page 2.

INTERNET *continued from page 29*

associated with a changing rate of FEV_1% predicted decline.
http://www3.interscience.wiley.com/journal/121430622/abstract?CRETRY=1&SRETRY=0

Selective Isolation of *Pseudallescheria* and *Scedosporium* Species from Respiratory Tract Specimens of Cystic Fibrosis Patients. R. Horré, G. Marklein, R. Siekmeier, S. Nidermajer, S.M. Reiffert. Respiration. Published online first

Fungi of the *Pseudallescheria/Scedosporium* complex are known to be colonizers and infectious agents of the respiratory tract of cystic fibrosis (CF) patients. Colonized CF patients are at high risk for the development of disseminated scedosporiosis after lung transplantation. The detection of these fungi may be difficult, because they grow slowly and so will be overgrown by faster developing microorganisms on the media routinely used in diagnostic laboratories. Our results suggest that standard microbiological media and procedures are not sufficient to detect colonization of the respiratory tract by *Pseudallescheria/Scedosporium* in CF patients. By use of SceSel+ agar, fungi belonging to this complex were isolated more frequently. Therefore, this semiselective mycological isolation medium should be used for the detection of these fungi in the respiratory tract of CF patients, especially in patients in whom a fungal infection is assumed or who are scheduled for lung transplantation.
http://tinyurl.com/83mcn5

***Pseudomonas aeruginosa* lasR mutants are associated with cystic fibrosis lung disease progression.** Lucas R. Hoffman, Hemantha D. Kulasekara, Julia Emerson, Laura S. Houston, Jane L. Burns, Bonnie W. Ramsey and Samuel I. Miller. Journal of Cystic Fibrosis. Article in Press

Pseudomonas aeruginosa with mutations in the transcriptional regulator LasR chronically infect the airways of people with cystic fibrosis (CF), yet the prevalence and clinical implications of lasR mutant infection are unknown. Culture positivity for lasR mutant *P. aeruginosa* may serve as a marker of early CF adaptive change of prognostic significance. Furthermore, as LasR inactivation alters susceptibility to antibiotics, infection with lasR mutant *P. aeruginosa* may impact response to therapy.

Former USACFA Director Cyndie Baker Nall

Cyndie Nall, formerly Cyndie Baker, died November 8, 2008, in Louisville, Kentucky. She was 62. Cyndie served on the USACFA Board of Directors from early 1997 to early 2000. She added a wealth of knowledge about CF to the group.

August 21, 1956 - November 8, 2008

Cyndie was diagnosed with CF in what she called the "Dark Ages of CF". She was six years old and it was 1952. She credited her parents for her long and productive life. She had bilateral lung transplant August 28, 2005, and felt it was a new chance.

Cyndie graduated from Florida State University, with a BS in Fashion Merchandising and Marketing. During her career, she taught school, was a buyer in a large department store, owned a children's specialty store and filled various sales positions. Also, she was a motivational speaker for many years. She was sponsored by the people who created and marketed "The Vest®". She traveled to education days and conferences all over the country to spread news of living with CF. Many of us met her at one of those meetings.

She loved helping others and trying to help them make the best of their lives. She always took time to talk with people and to encourage them in their dealings with CF.

Cyndie loved what she did. A quote from Cyndie was: "To love what you do and feel that it matters – How could anything be more fun?" You certainly proved that, Cyndie.

INTERNET *continued from page 30*

http://tinyurl.com/8gut4h

GENE MODIFIERS

Update on gene modifiers in cystic fibrosis. Collaco, Joseph M; Cutting, Garry R. Current Opinion in Pulmonary Medicine. 14(6):559-566, November 2008.

Cystic fibrosis (CF) is a common, life-limiting monogenic disease, which typically manifests as progressive bronchiectasis, exocrine pancreatic dysfunction, and recurrent sinopulmonary infections. Although the gene responsible for CF (CFTR) was described in 1989, it has become increasingly evident that modifier genes and environmental factors play substantial roles in determining the severity of disease, particularly lung disease. Identifying these factors is crucial in devising therapies and other interventions to decrease the morbidity and mortality associated with this disorder. Although many genes have been proposed as potential modifiers of CF, only a handful have withstood the test of replication. Several of the replicated findings reveal that genes affecting inflammation and infection response play a key role in modifying CF lung disease severity. Interactions between CFTR genotype, modifier genes, and environmental factors have been documented to influence lung function measures and infection status in CF patients. Several genes have been demonstrated to affect disease severity in CF. Furthermore, it is likely that gene-gene and gene-environment interactions can explain a substantial portion of the variation of lung disease. Ongoing genome-wide studies are likely to identify novel genetic modifiers. Continued exploration of the role of genetic and nongenetic modifiers of CF is likely to yield new options for combating this debilitating disease.

http://tinyurl.com/neapn

FYI

Anemia in Cystic Fibrosis: Incidence, Mechanisms, and Association With Pulmonary Function and Vitamin Deficiency. Annette von Drygalski, MD, PharmD and Julie Biller, MD. Nutrition in

Continued on page 32

Clinical Practice, Vol. 23, No. 5, 557-563 (2008)

Anemia in CF is associated with poor lung function and vitamin deficiency. Although anemia was often incompletely evaluated, iron deficiency was common. Recognition and complete evaluation of anemia might be important for continued improvement of care in CF.

http://ncp.sagepub.com/cgi/content/abstract/23/5/557

Alendronate Once Weekly for the Prevention and Treatment of Bone Loss in Canadian Adult Cystic Fibrosis Patients (CFOS Trial) Alexandra Papaioannou, MD, MSc; Courtney C. Kennedy, MSc; Andreas Freitag, MD, FCCP; George Ioannidis, MSc; John O'Neill, MB, BAO, BCh, MSc; Colin Webber, PhD; Margaret Pui, MD; Yves Berthiaume, MD, MSc; Harvey R. Rabin, MD; Nigel Paterson, MB, BS, FCCP; Alphonse Jeanneret, MD; Elias Matouk, MB, ChB; Josee Villeneuve, MD; Madeline Nixon, BSc and Jonathan D. Adachi, MD. *Chest*. 2008; 134:794-800

Alendronate (FOSAMAX; Merck; Whitehouse Station, NJ) therapy was well tolerated and produced a significantly greater increase in BMD over 12 months compared with placebo.

http://www.chestjournal.org/cgi/content/abstract/134/4/794

Peripheral nerve dysfunction in adult patients with cystic fibrosis. J. I. O'Riordan, J. Hayes, M. X. Fitzgerald and J. Redmond. Irish Journal of Medical Science. Volume 164, Number 3 /July, 1995. Pages 207-208

This study demonstrates that mild peripheral nerve dysfunction is common in patients with cystic fibrosis. With the improving long term survival of these patients we predict that the prevalence and severity of this complication will increase.

http://www.springerlink.com/content/71764133640q8626/

A novel solution for severe urinary incontinence in women with cystic fibrosis. J.M. Helm, H. Langman, M.E. Dodd, A. Ahluwalia, A.M. Jones and A.K. Webb. Journal of Cystic Fibrosis. Article in Press

Tension-free Vaginal Tape is a safe, effective and worthwhile solution for stress incontinence in females with cystic fibrosis.

http://tinyurl.com/7cfx24

Recurrent exacerbations affect FEV_1 decline in adult patients with cystic fibrosis. Anna Amadori, Andrea Antonelli, Ilaria Balteri, Anja Schreiber, Massimiliano Bugiani and Virginia DeRose. Respiratory Medicine Article in Press, Corrected Proof

Obstructive lung disease is the major cause of morbidity and mortality in cystic fibrosis (CF). To identify risk factors contributing to FEV_1 decline in CF patients, we carried out a retrospective analysis of clinical and pulmonary function data in a population of CF patients followed up for 5 years and studied the correlation between clinical data and FEV_1 decline. Both the number of exacerbations/year and the number of IV antibiotic

Calling All Writers

Have you written an article or story for *CF Roundtable?* If not, why haven't you written? Are you concerned that you may not be a great writer? Don't let that stop you. We have people who will work with you, on your article, to make it the best it can be.

Are you concerned because you can't think of a topic? How about if we give you a few ideas to start with? Here are some titles that go from head to toe and might pique your interest to write. Remember, these are only suggestions. You may come up with entirely different ideas and that is fine with us. All we ask is that you write about your experience with CF.

Here are a few possible topics for your use: headaches; understanding what you hear; pain(s) in the neck; arm twisting; the case at hand; a breath of fresh air; gut reaction(s); pain in the butt; oh, my aching back; getting hip to a subject; standing on one's own two legs; at the foot of the problem; toeing the line; my sole responsibility. As you can see, these are humorous suggestions that are meant to give you some ideas. You need not use any of these, but you may, if you wish. For other ideas, check out the Looking Ahead section on page 3. All submission dates for the coming year are posted there.

We ask that all submissions be typewritten. If you want to e-mail your submission, please have it in Microsoft Word or a similar program. You may send your submissions to:

cfroundtable@usacfa.com or to

USACFA
PO Box 1618
Gresham, OR 97030-0519

courses/year were strongly related to the FEV_1 decline. Patients with airway infection or with diabetes had significantly lower FEV_1 values during the study as compared with non-infected patients or patients without diabetes; however, both the presence of airway infection or diabetes did not affect the FEV_1 decline. These results suggest that the aggressive treatment of disease exacerbations is crucial for delaying lung function decline in CF.
http://tinyurl.com/8d5ds5

Cystic fibrosis and estrogens: a perfect storm. Zeitlin PL. J Clin Invest. 2008 Nov 20. [Epub ahead of print]

Irreversible destruction and widening of the airways due to acquired infections or genetic mutations as well as those of unknown cause are more severe in females. Differences between male and female anatomy, behavior, and hormonal state have been proposed to explain the increased incidence and severity in females with airway disease such as cystic fibrosis (CF); however, a mechanism to explain a sex-related difference has remained elusive. The data suggest that for about one week of a four-week menstrual cycle, women with CF will have a reduced ability to efficiently clear airway secretions, the buildup of which is a hallmark of CF. The authors suggest that these data warrant the testing of antiestrogen therapy in females with CF and propose an alternative avenue for CF therapeutic development.
http://tinyurl.com9hnj4w

ABPA

Treatment of allergic bronchopulmonary aspergillosis (ABPA) in CF with anti-IgE antibody (omalizumab). Kanu A, Patel K. Pediatr Pulmonol. 2008 Nov 13. [Epub ahead of print]

Allergic bronchopulmonary aspergillosis (ABPA) results from IgE induced pulmonary response to aspergillus species. Recognition and

Continued on page 35

CF Living: An Interactive Source for CF Information

Here is another resource that can help one stay up-to-date with the latest CF treatment information. The resource also offers support services for patients and caregivers and other specialized information that can make coping with CF a whole lot easier.

Check out *CF Living* (www.CFLiving.com), a free, online program that delivers customized educational material and resources to help people with CF and caregivers alike. Full of practical information, including tips for making the most out of healthcare appointments and staying compliant, *CF Living* provides a convenient way to stay informed about CF and helps you to work more closely with your CF care team.

By enrolling in *CF Living,* registrants will be able to take advantage of the following:

- ***A Personalized Care Team Discussion Guide* with tips for how to engage in an open dialogue with your Care Team members, along with suggested questions to help start an informed conversation**
- **A series of educational e-mails to help you learn more about cystic fibrosis and what can be done to manage it**
- **Access to online resources that may help you continue to learn about CF**

To enroll in *CF Living* or learn more about the program, visit www.CFLiving.com. The program was created by Genentech, Inc. as part of the company's continued commitment to providing information and resources to individuals with cystic fibrosis and their caregivers.

CYSTIC FIBROSIS RESEARCH, INC.

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The Power of New Possibilities:
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We are creating a video and photo montage for exhibit at our National Conference
The Power of New Possibilities: Growing Stronger and Living Longer with CF

Sofitel San Francisco Bay, Redwood City, CA

This project captures children and adults with CF engaged in physical activities of all kinds: skateboarding, playing in a band, or taking a stroll. Whatever you're up to, let's get together!

Why? By sharing your activity, you inspire and encourage others in our CF community to join in.
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- Send your questions of a general nature regarding legal issues that relate to CF to our legal advisor: **Beth Sufian, Esq., 811 Rusk Street, Suite 712, Houston, TX 77002-2807**.

INTERNET *continued from page 33*

management of ABPA is challenging in cystic fibrosis (CF) patients because changes in symptoms, lung function and chest radiograph are similar to that seen in CF-related pulmonary infection. Standard therapy for ABPA includes systemic steroids and adjunctive use of antifungal agents. Little has been published regarding the use of monoclonal anti-IgE antibody in those with ABPA. We report a CF patient with her third exacerbation of ABPA who was treated with monoclonal anti-IgE (omalizumab) antibody; she had unfavorable side effects with prednisone therapy. This therapy resulted in improvement of pulmonary symptoms and lung function not achieved with antibiotics or prednisone alone.

http://www.ncbi.nlm.nih.gov/pubmed/19009619

Laura is 61 and has CF. She is a Director of USACFA and is the Secretary. Her contact information is on page 2.

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Do you wonder when your *CF Roundtable* subscription is due for renewal? Have you wondered how to tell if it is time to renew? Look at your mailing label. Immediately after your name, there should be a date. That is your renewal date. (On the example, you can see that Kathy is due to renew her subscription in May 2009.) If there is no date or it says (COMP COPY), your subscription is due for renewal.

KATHY RUSSELL 5/09
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United Network For Organ Sharing (UNOS). Phone: **1-800-24-DONOR.** Call for information on transplant centers, access for all patients needing organ transplants and general transplant information.

Transplant Recipients International Organization, Inc. (TRIO): An independent, non-profit, 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: **TRIO, 1000 16th St., Ste. 602, Washington DC 20036-5705. Or call: 1-800-TRIO-386.**

American Organ Transplant Association (AOTA): Helps defray out-of-pocket travel expenses for transplant recipients. Helps to set up trust funds. For more information write: **American Organ Transplant Assn., 3335 Cartwright Rd., Missouri City, TX 77459-2548.** Or call **(281) 261-2682.** e-mail: **infoAOTA@a-o-t-a.org.**

ADA: To learn how the Americans with Disabilities Act (ADA) applies to you, contact the Disability Rights Education and Defense Fund (DREDF) at **1-800-466-4232** between the hours of 9 a.m. and 3 p.m. Pacific Time. The DREDF has received a federal grant to inform individuals, who may be subject to discrimination, of their rights and remedies. To report a violation of the ADA, call the Equal Employment Opportunity Commission (EEOC) at **1-800-669-3362.**