An Important Clinical Trial for Lung Transplant Recipients

Each year, lung transplantation is a life-saving procedure for people with serious lung diseases. However, lung transplant recipients are at high risk for a life-threatening complication called chronic rejection. Chronic rejection is an immune response that leads to worsening lung function and organ failure. There are currently no therapies approved to treat chronic rejection. Developing a better understanding of chronic rejection and finding ways to prevent and treat rejection is one of the most important areas for research in the field of lung transplantation.

The good news is that many of North America’s leading lung transplant centers are currently recruiting patients for a clinical trial to evaluate the effects of an investigational drug called cyclosporine inhalation solution (CIS). The goal of the study, called CYCLIST, is to determine if CIS can safely reduce the occurrence of chronic rejection and extend life in lung transplant recipients.

Cyclosporine inhalation solution (CIS) is an inhaled formulation of cyclosporine, an oral medication that has been available for over twenty years to prevent rejection in transplant recipients. Inhaling cyclosporine provides a higher concentration of the drug directly into the lungs. CIS was originally developed and studied at the University of Pittsburgh beginning in 1988. Scientists have conducted nine preliminary studies in lung transplant recipients including a study published as the lead article in the New England Journal of Medicine.

Participants in the CYCLIST study will be making an important contribution to lung transplant medical research and will be eligible to receive the drug at no cost for life as long as the drug is still under investigation or is FDA approved. You may be eligible for CYCLIST if you are an adult on the waiting list to receive your first lung transplant or received your first transplant within the past two months at a participating center. More information about the study is available at www.cycliststudy.com or through a participating transplant center.
A WORD FROM THE PRESIDENT...

L ast month I made a decision to retire at the ripe old age of 51. I wondered for months if it was the right decision. The writers on our FOCUS topic (Career Choices) in this issue, significantly helped answer that question, and I now know in my heart it was the right thing to do. In these current economic times, decisions like this become even tougher to make. With unemployment approaching 10%, and people really out of work closer to 15%, one knows if that decision is a wrong one; the competition to re-engage in the workforce is as challenging as ever.

In her Speeding Past 50 column, Kathy Russell provides feedback on our focus topic. While her personal story is intriguing, don’t let this super volunteer fool you. In her 33 years of ‘retirement’ she has touched hundreds, if not thousands, of lives (including mine) in the most positive of ways.

We have seven additional FOCUS articles. The first one I read, from Anthony Weiss, really hit home. It turns out that he retired exactly one month before I did, and after reading his article, I feel even more comfortable in my decision to retire. Maggie Sheehan, at the tender age of 21, ponders what career is best for her. I remember pondering that question in my mid-40s!

Debra Radler discusses her accounting career and, more importantly, how her employer worked with her to address her health issues throughout her career. I wonder how many other employers would do so if we simply asked? Dr. Jeanie Hanley proves you can choose any career you want to choose, at least for a time. Her career path is an interesting read. Andrea Eisenman provides some insights into her career and her outstanding contributions to many organizations, including USACFA, as a volunteer. Rich DeNagel walks us through the ups and downs of working and career search while having CF. All our focus writers talk of the importance of taking care of you as a first priority. Dr. Julie Desch suggests a very logical approach in determining what might be the best career choice for someone with CF, or anyone for that matter, by focusing on your strengths. Her Wellness column is filled with practical advice.

Beth Sufian offers some wonderful advice to all of us with CF in Ask the Attorney. She covers the impact of the decision to stop working and the complex Medicare coverage for nebulized meds almost all of us take during our life struggles with CF.

Rich DeNagel interviews Maggie Sheehan in Unplugged. Maggie is one of the youngest directors USACFA has had and I believe you will find she has matured well beyond her age.

Isabel Stenzel Byrnes writes about the Great Outdoors in Spirit Medicine. Her insight into nature, the internal spirit, and the interdependence of things both natural and unnatural is extremely provocative. Enjoy her article, and our entire newsletter.

Peace,

[Signature]

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
Colleen Adamson
Alexandria, VA
40 on March 8, 2009

Lisa Cissell
Bardstown, KY
46 on March 8, 2009

Kristen Thompson Miller
Carencro, LA
28 on January 22, 2009

Kate Perry
Gloucester, MA
39 on January 31, 2009

Kathy Russell
Gresham, OR
65 on April 17, 2009

Maggie Sheehan
Chicago, IL
21 on March 27, 2009

Transplant
Paul Albert, 49
Catasauqua, PA
Bilateral lung
16 years on February 10, 2009

Wedding
Kristen & Bobby Miller
Carencro, LA
4 years on November 13, 2008

Kathy & Paul Russell
Gresham, OR
44 years on March 27, 2009

NEW BEGINNINGS

Engaged
Anabel Stenzel & Prentiss Trent Wallace
Redwood City, CA
Engaged on February 21, 2009
Wedding date to be announced

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

Spring (current) 2009: Making Career Choices with CF.

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) There are many problems with having CF that can be directly related to one’s gender. Do you have any questions about or experience with any of these issues? Please share with our readers.

Winter (February) 2010: Diet and Nutrition. (Submissions due December 15, 2009)
At a time when there are millions of people who have lost their jobs and insurance coverage, people with CF need to understand their rights to government benefits. I want to make sure that people with CF who are filing applications for Social Security have strong applications so that their applications are approved on the initial try. People mistakenly believe that no matter what they do, their applications will be denied. This is UNTRUE. I have helped four people with CF with their initial applications in the past month and all four applications were approved in two weeks! It helps to know how to complete the application and what information to provide to SSA. Please let me know if I can answer your questions. Also I hope all of you will read Anthony Weiss’s article in this issue about deciding to stop work. This is an extremely difficult decision for an adult with CF. Anthony does an incredible job telling his story that hopefully will help some of you deciding if now is the right time to stop work and spend more time taking care of yourself.

1. Are TOBI® and Pulmozyme® Covered under Medicare Part B or Part D? Medicare regulations require that FDA approved prescription drugs used with durable medical equipment be covered by Medicare Part B. TOBI and Pulmozyme are used with nebulizers, which are durable medical equipment, so are covered by Part B. There are a limited number of drugs currently covered under Part B. Many pharmacies are not familiar with Part B coverage for this limited number of drugs. It is helpful to use a pharmacy, such as the CF Services Pharmacy, that is familiar with the processing of Part B prescription drug coverage. The CF Services Pharmacy can be reached at: 1-800-541-4959. CF Services is knowledgeable on the filing of Medicare Part B and D claims for people with CF.

If a drug is covered by Part B it cannot be covered by a Medicare Part D plan. However, some people who do not have a diagnosis of CF use drugs like Pulmozyme and TOBI. TOBI and Pulmozyme have been approved by the FDA for use only by people with CF. Therefore, a person who does not have a diagnosis of CF but has a prescription for TOBI or Pulmozyme would obtain coverage for the drugs under their Medicare Part D plan. This confuses people with CF who may go on-line and check to see what drugs a Medicare Part D plan covers. When a person with CF sees TOBI and Pulmozyme listed as a covered drug under a Part D plan, the person mistakenly believes that their prescription of TOBI or Pulmozyme should be covered under Part D. This is incorrect. The drugs should be covered under Part B. Since the drug must be FDA approved, a drug like Colistin, that is used off label and has not been approved by the FDA for use in a nebulizer, would not be covered by Medicare Part B but would be covered by Part D.

If a person needs assistance with the Part B co-pay, there is assistance available from a variety of sources. The CF-Patient Assistance Program began operating in the past few months and can be reached at: 1-888-315-4154. It is a subsidiary of the CF Foundation. The Medicare Part B and Part D coverage issues are complex and specific to CF. Often Medicare Part D plan customer services representatives are not familiar with the different coverage issues for some of the drugs used to treat CF under Medicare. Please contact the CF Legal Information Hotline if you have additional questions.

2. I am a single 30-year-old and currently work and support myself. I am wondering what I can do now
to prepare for a time when my
health may require me to stop
work. I applaud your question. I think
it is great you are planning ahead. Too
many people with CF think that their
ability to work will last forever. While
no one knows when a person will
become unable to work, it always is
good to be prepared. Saving money is
very important. I do not mean to
imply I am a financial wizard. Any
book on financial planning will sug-
gest saving money. There may be a
period of time when no benefits are
being received after the person with
CF stops work. Social Security
Disability Insurance (SSDI) benefits
start five months after the person
becomes unable to work. A person
with CF should try to have savings
that will cover living expenses for five
months. Having money in the bank
will help supply the funds needed for
living expenses during this time. In
addition, making sure that your
monthly debt is manageable is a good
idea. For example, monthly expenses
that use all of your monthly wages
may not be the best idea. Some peo-
ple make just enough money from
work to pay for their basic living
expenses. Those individuals do the
best they can to live on a small
amount of income from wages.

I admire my friends with CF who
have a very limited income and seem
to make do with what they have each
month. I learn from their ability to
budget and spend wisely. However,
some people with CF have an income
that results in extra income after basic
necessities are purchased. Sometimes
those individuals buy expensive cars
and have large car payments and/or
purchase houses whose mortgages
take most of their monthly income. If
the person becomes unable to work,
the person then is unable to pay the
mortgage and loses the house or car.

One good thing about the eco-
nomic downturn may be that people
with CF, and others, evaluate their
spending habits and set more money
aside each month for savings. Instead
of purchasing a car with a $500
monthly payment, perhaps a car pay-
ment of $200 a month is a better idea.
Anyone who has read the newspaper
or watched the news has heard about
the millions of people who took on
too much debt and who, when faced
with the loss of their job, were unable
to pay their monthly obligations. At
the risk of sounding too “preachy”,
people with CF, especially our young
adults, can learn from these reports
and try to spend moderately and save
money for a rainy day.

There is almost no chance a per-
son with CF will be able to buy a pri-
vate long term disability (LTD) poli-
cy. There are no federal laws that
require an insurance company to sell a
LTD policy to anyone who wants to
purchase such a policy. Whenever I
have written about the difficulty in
obtaining private individual LTD
policies I receive one or two e-mails
that tell me if a person lies on their
application for benefits and does not
disclose the diagnosis of CF, the per-
sion will be able to purchase an LTD
plan. So, just to clarify, I am not talk-
ing about what will happen if you lie
on an LTD application. I am talking
only about providing truthful infor-
mation on the LTD application. Some
employers offer LTD policies without
requiring a medical exam. If an
employer provides an LTD policy,
hopefully, an employee who has CF
has enrolled in such a plan. We hear
from people with CF who say that
their employer offered LTD coverage,
but the person with CF did not think
that their health would ever prevent
them from working. The person with
CF did not sign up for the LTD cover-
age. Hopefully, no one who reads CF
Roundtable will make this mistake.
Anyone can become unable to work
due to health issues, especially people
with CF. Enrolling in an employer’s
LTD plan will not make a person
become unable to work. Employers do
not have to offer an LTD plan. If you
are lucky enough to have a job that
offers an LTD plan, please enroll.

If a person becomes unable to
work, then the person can apply for
SSDI. If the SSDI application is
approved, the person will become eli-
gible for Medicare 29 months after
they stop working. It is important to
have the funds to pay for COBRA,
which allows a person employed by an
employer of 20 or more employees to
continue the employer-based health
insurance coverage until the person
becomes eligible for Medicare. When
the reason a person stops work is to go
on SSDI, as long as the person is
approved for SSDI within the first 18
months of stopping work, the person
will get an additional 11 months of
COBRA to bridge the gap until the
person is eligible for Medicare.

3. I have worked for 10 years
but think I will have to stop work
soon, due to the need to spend
more time taking care of myself. Do
you think I should put my savings
into a special needs trust to qualify
for Medicaid? A person cannot qual-
ify for SSI or Medicaid if his SSDI
check is more than the SSI amount in
his state. Before you take any steps to
put your savings into a special needs
trust, make sure your SSDI check will
be below the SSI amount in your
state. A special needs trust is used to
keep savings over the $2000 SSI indi-
vidual savings limit from disqualifying
someone for SSI benefits. However, if
your SSDI check is more than the SSI
amount in the state YOU WILL NOT
BE ABLE TO QUALIFY FOR SSI.
For example, if a person has worked
10 years, his SSDI check may be
$1000. If the SSI amount in the state
is $674 then the person CANNOT
Continued on page 15
Spring is upon us. We have survived another long, cold winter. The sunlight beckons us. My favorite part of warmer weather is being outside. I love to explore open spaces and admire the fresh air, wildflowers, and greenery. Walking and hiking are great workouts for my body. But I mainly seek the outdoors because it is healing to my spirit.

Studies show that greenery actually is good for the spirit: planting trees and lawns in inner-city housing projects makes residents feel greater calm, focus and well-being. I’m drawn to nature for a variety of reasons: a desire for connection, perspective on living with cystic fibrosis, and because of the spiritual lessons the natural world teaches me.

First, I’ve examined that everything about my life with cystic fibrosis is completely unnatural. I was kept alive with enzymes, chemicals, devices, and now, someone else’s lungs. I can’t even digest food without an unnatural supplement or an unnatural injection. I have spent cumulatively about 65 weeks of my life in the sterile concrete walls of a hospital, artificially sustained with antibiotics, machines, and surgeries. At these times I feel most divorced from nature and I yearn for a reminder that I am still part of the natural order of things.

That is why I seek solace from my unnatural existence from the natural world. Thanks to my father’s influence, I have learned to replenish my spirit with a connection to plants, the land, and the sky. I grew up camping and hiking with my family in the local mountains, and loving every minute of it. With effort and planning, CF did not keep me from the outdoors. I used a generator, boat battery, portable nebulizer and, eventually, liquid oxygen to run a nebulizer from the tent. Now, post-transplant, I just pack my pills and insulin and can backpack into the wilderness – with Purell®, salty snacks and high calorie food.

Given certain precautions, being in nature can be healing for my lungs. I used to wear oxygen in my backpack and hike. I would go slowly and cough constantly, leaving a trail of phlegm to fertilize the soil. I felt liberated spitting in nature because no one would stare or walk away. After the hike I was exhausted, but for the rest of the day I could clear more from my stretched lungs than I could with any mucolytic drug. Now, post-transplant, I can breathe outside air without the fear of inhaling germs from a crowded, enclosed space. As far as I’m concerned, anything healing for the body is also healing for the spirit. I gain confidence that I’m proactive about taking care of my body.

In the last column of Spirit Medicine, I wrote about my fear of dying. Being in nature offers a reminder that the amount of time I live is all relative. Last year, my sister and I drove through the national parks of Utah. We stood, mouths gaping open, arms stretched wide, on 1000-foot high cliffs overlooking layer upon layer of colorful geology that was formed 225 million years ago. I felt comforted by timelessness. We humans are just a speck in time. My life seems so insignificant compared to the life force of the universe. For a moment, whether I have CF or health insurance, a job or good PFTs, doesn’t matter. Even whether I live or die doesn’t matter. When I die, I will return to the earth. The land goes on.

I agree wholeheartedly with John Muir who says, “Our flesh-and-bone tabernacle seems transparent as glass to the beauty about us, as if truly an inseparable part of it, thrilling with the air and trees, streams, and rocks, in the waves of the sun - a part of all nature, neither old nor young, sick nor well, but immortal.”

At Canyonlands National Park, I hiked to the top of Aztec Butte and was greeted by a cave with Ancient Puebloan ruins. These disappeared people, from 1200 AD, endured good times and bad just as we do today. They struggled with illness and loss,
too, and more of it, than we do today. To live to be forty was a grand accomplishment. Whatever I’m going through has been experienced before. I am part of something much bigger than myself.

According to psychologist Dachler Keltner, humans evolved to feel awe of nature because it is beyond our control and understanding. He believes that experiences like staring up at a magnificent redwood tree or watching the sunset, diminish ourselves and remind us of how limited each of us is. The emotion of awe is a survival instinct because it reorients our interconnection to the earth, and gives us reverence.

When I stood on a peak overlooking the entire Yosemite Valley last September, I wondered, “Where did this all come from? Who created this?” The mystery and sacredness makes the outdoors my church. There is something more powerful and all-knowing in change here. In other words, I see God in the squawks of birds, in the scent of blooming wild lilac, in the breaking waves of the ocean. I can’t help but feel grateful to God for the chance for my senses to absorb the treats of this world.

The outdoors also instructs me on valuable spiritual lessons. For example, nature shows me that I can never know what to expect. Nature offers surprises: around the corner of each trail is a gift - a wildflower, a lake, a magnificent view. There is always something to look forward to. Or, conversely, there is a rainstorm, a mountain lion, a rattlesnake ahead. We can expect either, and prepare ourselves to deal with both positive and negative.

I remember a walk I took a few weeks before my transplant. I was an inpatient and sicker than I’ve ever been. Wheeling a high-flow oxygen tank, I exited the hospital and walked slowly - step, breathe, step, breathe - to a hidden cactus garden across the street. It was the hardest walk of my CF life. When I got there, all I could do was sit on the bench, inhaling the refreshing air. As tough as this walk was for my body, my spirit was nourished. I admired the frost on the spiny plants, savoring this visual candy. I wondered if this would be my last walk outdoors. I had no idea what kinds of walks I would eventually take outside, with new healthy lungs. At the moment, the next ‘trail’ was unimaginable.

Another lesson I derive from nature is about interdependence. Sometimes I get down on myself because my illness has caused me to be so dependent on others for help. I have relied on my parents, my husband, and the government to support myself. I want to take care of myself. Then I remember that nothing in nature exists independently. A flower does not grow on its own; it relies on the assistance of the sun, the rain, the soil, even bees to disperse its pollen. In its dependence, the flower is deeply connected...and just as beautiful.

When I find myself frustrated because CF imposes a restriction in my life, nature reminds me to chill out. The natural world just exists as it is. The sagebrush, the coyote, the Indian Warrior flower, do not, as a great naturalist and writer Ed Abbey says, “…sweat and whine about their condition, they do not lie awake in the dark and weep for their sins.” Nature reminds me to resist less, accept more, to just be. A Buddhist teaching says, “Sit, then, as if you were a mountain, with all its unshakable, steadfast majesty. A mountain is completely relaxed and at ease with itself, however strong the winds that batter it, however thick the dark clouds that swirl around its peak.” That’s hard to do, but it’s a great goal to have.

Nature teaches my spirit about impermanence. Change happens outdoors. I’m taking wildflower docent training at a local natural preserve. Every week this spring, plants are blooming and growing. In a short time the scenery is completely different. There is even much change in a single day. Dusk comes without any hesitation. It comes with great beauty: the sky lights up with orange splashes on a purple canvas, just as the first star appears in the distance. The normal rhythms and patterns in nature remind me that human life has the same. If I’m sick (or well) it doesn’t mean I’ll stay that way. It’s up to me to allow my mind to accept the normal cycles of life, and to remember that, with each season, there is something to appreciate.

I find peace when I’m in nature, but let there be no idealization about the wild. Nature can be vicious, unremitting, fatal. Untreated cystic fibrosis is a natural biological phenomenon that is merciless. Rigor mortis, tape worm, gangrene, and cholera are all natural processes that offer no perspective, no acceptance, and no beauty. In harsh climates, I feel the power of a force that can easily overtake me. I fought fierce, bitterly cold wind along a trail in Tallgrass Prairie National Preserve in Kansas, last fall. I’ve felt oppressive summer heat and thirst walking at Saguaro National Park in Arizona. I once wandered at dusk in knee deep snow during a brutal blizzard, sure that poor judgment could place me minutes away from a long, dark night and hypothermia.

Untamed nature incites a fearful spirit because it threatens our physical survival. Sometimes, I counter this fear by centering on my spiritual resilience. When I summit a mountain, struggling to breathe, muscles burning, I focus on my perseverance. Enduring discomfort is a reminder of my strength - blisters, pain, fatigue are all good signs of my spirit’s overcoming a challenge. This optimism is war-
Career planning is so important for everyone, but it is doubly so for people who have chronic health problems such as CF. We can choose to work at something that is fun, or interesting, or exciting, or challenging when we are young, but that may prove to be “undoable” for us as we age. We can choose something that is safe, i.e.: does not pose any health risks to us. We can “fall into” a career or we can move from job to job. There are many ways to approach how we support ourselves.

I strongly recommend that each of us get good career counseling, to help us make an informed decision that we can live with. There are so many factors to include that help is not only wise but is essential. We need to think of how our health will be affected by the surroundings, the co-workers, the others with whom we might come into contact, the rigors of the actual work and the hours that we must put in. We need to remember that most employers don’t want someone who is rarely available for work, so we must do our best to stay as healthy as possible.

Some jobs may sound wonderful to us but may prove to be far from the best choices. I wanted to be a nurse. I went to school for that career. I loved my work (most of the time) but had to leave it because of my health. I was getting too sick, too often, and missing too much work. It wasn’t good for my employers or for me.

I applied for Social Security Disability Insurance (SSDI) but was denied. The judge said that surely there must be some kind of work, somewhere in this country, that I could do for at least a few hours a week. After much discussion with my husband and my doctors, we decided that I would stay at home and make staying well my life’s work. For me, that was a good decision. I “retired” 33 years ago and I still am alive.

Perhaps, if I had made something else my career of choice, I might have been able to work these past 33 years. I would have liked that, in some ways. I would have been able to show that I was a productive member of civilization. I would have had the satisfaction of knowing that I was doing something that someone else was willing to pay for. I could have added a substantial amount of income to our joint earnings and that could have made life easier, in some ways, for both my husband and me.

So what would have been a better career choice for me? Should I have been a secretary? No, I don’t like that kind of work. Should I have been a teacher? No, I really don’t like to spend that much time with kids. Should I have been a something else? Yes, I am sure that there is something that I could have done that would have been interesting and challenging, and that would have allowed me to work for an entire career. In today’s world I might have done something in the computer field. There are so many jobs in that world that do not take great physical exertion and offer lots of mental exercise, not to mention good pay and benefits.

Benefits that are offered by employers should be considered when making job decisions. Some employers offer good medical care, at a reasonable cost, that can make our lives much easier. Others will offer good insurance but at high costs that can...
really cut into one’s earnings. Still others will offer very little in the way of health care but may pay well enough to offset the costs of getting some kind of health coverage. There are so many things to think about, when making career choices.

Another consideration is what kind of physical exertion is required and how long can I do that? When we are young, we may have loads of energy and be able to do something that is really physical. As we age, and with the changes that may occur in our health, we may not be able to keep up with the job requirements. This may cause either a job change or some other accommodation. I know how hard it is to have to give up doing something that you enjoy, but it is possible to make such changes and go on.

In the years since I stopped getting paid for work, I have done a lot of volunteer work. I helped raise funds for the CF Foundation and also procured food for CF Camps. I was a volunteer with my city, working with crime prevention. I was able to take classes from the FBI in “Crime Prevention Through Environmental Design” and was able to give classes about that to citizens of my city. I also gave Neighborhood Watch classes throughout my city. Giving these classes gave me a chance to meet a lot of my neighbors and to give back to my city.

Another way that I spent time was volunteering on the Neighborhood Accountability Board. This was a system to help children who had broken the law to pay back without getting a Juvenile Court record. It didn’t take much of my time but was very rewarding.

I really enjoy photography and "shot" many weddings and family gatherings. I loved doing portrait work and got great satisfaction from producing photos that really captured the essence of my subjects. When that got to be too exhausting, I had to stop making commitments for special dates. I couldn’t be sure that I would have the energy to do a good job when the time came, and I certainly didn’t want to let anyone down. My new digital equipment makes photography much easier, but I still can’t do it like I used to.

I would say that my main career for the past 33 years has been to take the best possible care of myself and my health. I find that that can be a full-time job. As I age, my healthcare needs get more time consuming. Also, I get tired more quickly than I used to and take longer to recover. I am sure that trying to hold down a job would have been very difficult for me, even 10 or 15 years ago. Now, I know that I couldn’t do it. If I do something on any given day, I will need a couple of days to rest and get back some energy. Oh, well, I am alive and what could be better than that?

If you are still in school, please talk with your guidance counselors about education and training for whatever you want to do. I hope they are more knowledgeable than my counselors were. If they have good information, they can make your decision making much easier. I wish that my counselors had told me of some options that existed for me. I did not know about certain types of scholarships for which I could have applied. I might have had a very different career choice, if I had known. Ah, well, no use crying over spilt milk.

I should mention that another volunteer position that I have filled is with the organization that publishes this newsletter. In February 1990, a group of us began the investigational work that was required before the United States Adult Cystic Fibrosis Association, Inc. (USACFA) could be formed. In the 19 years since then, I have served as Treasurer, President and Director of USACFA. My husband and I have done most of the mailing chores for all those years. We keep all the back issues and take care of getting those out to the people who order them. I still put in a few hours each week with USACFA chores and I think it definitely is worth the effort.

The time I have spent with USACFA makes me think that I might have studied something to do with printing or publishing as a career. I think I might have liked that. I know that it would have been interesting.

So, it would appear that although I have lived a long time and (I hope) I have learned much along the way, I still do not have good answers for anyone on how to choose a career. I think I will stick with the suggestion to utilize guidance counselors and to be aggressive about getting information on scholarships and other types of helpful programs.

Now, I am off to enjoy spring. I turned 65 on April 17th and feel so fortunate to be alive. I hope you all have a great spring and I’ll see you next issue. ▲

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

I f I were a healthy bodied person, I would be writing an entirely different article about career minded decisions. It would include following your dreams and making sure that you spend your life doing that for which you have passion. But I am not a healthy-bodied person, so my career decision needed to be based a little less on the passionate and a little more on the practical. The past 25 years have sometimes been fraught with second guessing my decision. I often wished that I could be one of those people who bolted out of bed in the morning and skipped with joy to her job. But despite intermittent periods of discontent, overall the decision has been one of the best of my life.

When I was young and aspiring, I set my sights on the money. I wanted a career in the business world that held opportunities for women and could generate a fair amount of cash for me to enjoy the fruits of my labor. I also was very shortsighted. My CF instilled in me that goals should not span decades, but more like months. And although I originally entered college with the belief that accounting would be my career nesting spot, I soon realized that I was much more of a right-sided thinker and that accounting and business, in general, was going to be a struggle.

When I was a junior in college, I approached my father with the brilliant idea of changing majors to something a bit more on the creative side, and I watched him hit the ceiling. His best interests for me were always motivating him, and he truly believed that a woman in the ‘80s had far more potential to earn a living as an accountant than as a “basket weaver”. I don’t ever remember presenting the option of basket weaving to him, but in his mind, anything bordering on right-sided brain use was “basket weaving”. He, obviously, was a left-sided thinker. So, dutifully, I listened to my father and attempted to conquer the world with my newfound knowledge of debits and credits.

As feared, the introduction into the world of brilliant businessmen and women, and accounting superstars who could recite tax code with vigor and animation, left me realizing that I was a fish out of water. I knew that I should run, but something kept me grounded. Whatever that something was - fear, laziness, earnestness, responsibility, desire to please my parents, need for insurance or a combination of all the above - it rooted me. And like a tree, I am still standing exactly where I started 25 years ago, with the same firm, in the same career.

I joined my firm with a fair degree of ambition. I sat for the CPA exam, I passed it and I worked hard the first five years climbing up the vocational ladder. But public accounting is stressful. It is laced with deadlines and a philosophy that for four months out of the year, known in the biz as tax season, commitment to your work will surpass any other commitment in life. I’m truly amazed how many people are able to abide by that philosophy. I have never been one of them. Perhaps it is because my commitment to my health has always had to surpass commitment to anything else. When it was becoming obvious to me that the fruits of my labor were landing me on my sick bed more often than acceptable, I had to readdress the importance of making money and achieving vocational success. It suddenly was not as important to me as maintaining my health.

So I approached my employer…

“I may have sacrificed passion for practicality many years ago, but the payoff has been exponential.”
with my plan to work part-time and cited health concerns as the primary reason. They were wonderful about it. This is where the career is not as important as the employer. My employer has been as accommodating to me and my needs as any parent would be to his child. It has been a blessing.

I have the kind of job that does not require me to show up everyday. I am not in private industry where payrolls have to be met and bills have to be paid. I oversee a select number of accounts. I keep their records current, I provide financial statements for them, and I prepare their tax returns. I schedule myself to go out and visit when it suits me, and all of my clients are aware of my health needs and accommodate me as well. When I was young and aspiring, I started work at five minutes to 9 a.m. Now, I start work at five minutes to noon. I work my hours as I can, and I work them around all my daily therapies and bouts with illness. The past five years have offered me more opportunities to be productive, because technology now allows me to work from home and tap into the office network. They rarely see me.

I don’t mean to imply that this is the norm for the business world. It is not even the normal policy for our firm. It is a special niche I’ve carved for myself because of many years of loyal service and an understanding that my health has to come first. Not everyone is this lucky.

I will never be one of those public accountants driving the BMW. I won’t have the word “partner” next to my name. I have had to accept a certain degree of vocational mediocrity and my ego has had to adjust to years of watching my peers and my subordinates pass me by. That has been the price. But thanks to my father’s foresight, I have been able to earn a respectable hourly wage that allows me to support myself without deprivation on a part-time schedule. And there is nothing like being able to sleep in most mornings, and take a couple of months off in the summer, and show up and work when my body allows it.

I may have sacrificed passion for practicality many years ago, but the payoff has been exponential. My decision has afforded me time to myself to pursue whatever passions I may desire — a coveted commodity in today's world.

For as certain as I’ve been over the years that my dream job had eluded me, I can now say that dreams always have a way of coming true. ▲

Debra is 46 and has CF. She is a part-time CPA living in Roselle, IL. She is stepmother to David and Nicole, wife to Adrian Gulinski, and mom to two dogs, Jasper and Jordan.
On January 30, 2009, I retired after 15 years working as a commodity lumber trader. Before going on disability, I was the manager of a 10-person department, supervising our daily trades and speculative positions and co-managing our futures hedging program. This decision to retire took me over 1 ½ years to make as I struggled with the pros and cons and consulted with friends, family and doctors.

Over the last few years my health was starting to deteriorate, as the frequency of my IV antibiotics increased and my energy level decreased. My daily routine consisted of waking up at 5:50 am, an abbreviated aerosol and vest therapy, weight lifting at the gym, work from 8am to 5pm, a complete aerosol and vest therapy, dinner, followed by passing out. Weekends were mostly spent on the couch, after sleeping in bed for 12-plus hours, both Saturday and Sunday.

Throughout my career, I had time for two things: work and sleep. My social network had shrunk because my extreme fatigue allowed me to only go out on Saturday nights, assuming my health permitted. Needless to say, my wife and I spent most of that time alone together. Even though we had no kids (I take my hat off to those who do), I just didn’t have the energy.

As I debated the merits of going on disability, I realized that stopping work would likely lead to reduced fatigue, fewer IV antibiotic treatments, and more time to perform aerosolized and chest physical therapy. On the other hand, I would have to acknowledge that I couldn’t keep up with those healthy individuals around me. In essence I would have to acquiesce and allow CF to take control of my life and dictate what I could and could not do. This would be a departure for me as I have always felt that CF is a part of my life but can be managed and not dominate my life.

Why would somebody with cystic fibrosis jeopardize his health and quality of life to maintain a normal work schedule? That requires a little visit to my past…

You may know the story of Mary Weiss, whose middle son at age 4 misunderstood his mom’s fundraising efforts for cystic fibrosis and the story of Sixty-Five Roses was born. If you aren’t familiar with this story, just Google “sixty-five roses” or go to: www.cff.org/AboutCF/Foundation/About65Roses/. That 4-year-old was my middle brother, Richard, who is now 47. The three boys, Arthur, Richard and Anthony (yours truly) were all born with cystic fibrosis.

Back in the 1960s, when my mom had been informed that the average life expectancy was only seven, she made a decision which ironically would make my decision 43 years later so much more difficult. She chose to raise us with normal aspirations such as college, careers, spouses and children, and reinforced that we do everything possible to live a normal life.

Despite the therapies, medications, surgeries, sickness, etc., she was not deterred nor did she allow us to give up our dreams to lead a fully productive, normal life. It didn’t matter if the odds were stacked against us. She wouldn’t accept “no” for an answer and expected us to carry our own workload and be contributing members to society.

Thanks to her encouragement, the three of us completed high school and college. I continued my education to get an MBA. Eventually we were all married and my oldest brother, Arthur, even had a daughter.

All three brothers were working together as lumber commodity brokers when Arthur, my oldest brother, died at the age of 36 in 1996. It was a heavy burden on both Richard and me, but we knew that we had to continue on with our lives. It was a stark reminder for me that in the years to come, we would be senior citizens in the CF community, and both the quality and longevity of our life would be diminished.

As we continued to work, Richard started suffering complications from CF and started to miss many months of work. However, he refused to retire as his role of “big brother” took on an added dimension with the loss of Arthur. Despite his failing health he continued to work part-time for five years until we almost lost him in December 2007. It wasn’t until that final incident that he, reluctantly, finally agreed to stop working.

So, now I have had two brothers with cystic fibrosis leave work only when their poor health had reached
near critical mass. I would have been an idiot if I didn’t learn from their history. I decided in my last year of work to reduce my work hours from 40 to 30 to 25 hours per week. During that time, I focused on longer treatments and more rest. While the company was supportive, there was an ongoing concern that I would have to give up my responsibilities.

In my mind, the job had defined who I was. I wasn’t only giving up my responsibilities but also my identity. I was anxious and fearful about my own self worth. But what I didn’t expect to taste was the freedom of taking care of myself and listening to my body. I never realized how much I was pushing myself until this point, as I had never really balanced my normal work life with my CF medical regimen.

Finally, last December, I notified my company that I would stop work permanently - effective January 30, 2009. I am now exploring a new chapter in my life at the ripe old age of 43, a retired senior citizen in the CF community.

It is this renewed interest to expand my horizons and give back to the community that prompted me to write this article. While partially I fear that I have lost my identity, and am unsure how my days will be challenged in the coming weeks and months, I know that I have chosen the right course. I write this article to encourage those who are wrestling with this decision to seek out-side input and be open-minded while learning from those who have preceded us. May you have the wisdom and courage to make this difficult decision before it is thrust upon you.

Anthony is 43 and has CF. He has been married to Nancy for 14 years. They live in Tampa, FL. where they enjoy Duncan, their dog, and, Nathan, their cat. Anthony’s pastimes include weight lifting and tennis as well as his most recent hobby of remote control airplanes. He can be reached at: atunsu@tampabay.rr.com
Where to begin? First, considering my CF, I never really thought I would have a career. My main stumbling block was that I never planned ahead; I always lived from one day to the next, thinking that I didn’t have much of a future to look forward to. Having a career really never seemed to be a realistic option.

Throughout my 20s, I moved through the world preoccupied, and went from one job to the next. I chose jobs that seemed interesting and, almost without realizing it, found what would become my career. In short, taking on a career has been a roller coaster ride. But it’s also been incredibly rewarding. At least for the moment, I’m enjoying the ride.

When I graduated from college I was in pretty good health and ready to take on the world. Little did I know what I was in for with the pressures of work, making ends meet, and keeping up with my treatments and health. Starting out, I naively jumped into teaching; a challenging profession under the best circumstances. Eating and treatments soon became optional, which landed me in the hospital about three months into my new job. My weight and PFTs plummeted, and I was in for about four weeks. I was able to keep my job but was introduced to the confusing reality of insurance policy fine print, sick days and employee disclosure issues.

Did I learn my lesson? No, not really. I wanted to prove I was just like everyone else; I was not going to let CF slow me down. The big lesson I did learn was that CF doesn’t control me, but it does require a great deal from me. This lesson is one I have had to learn again and again.

After a few more years in the classroom, I transitioned to a job in social services; and in particular, with a homeless shelter. I was getting better at managing things, and my health seemed to be leveling out. But I also continued to push the limits, and myself. Another reminder about having a career is that even the best laid plans are just that.

Reality stepped in again when I contracted TB. In four weeks, that was not good. I was quarantined in my small New York apartment for three months and out of work for almost a year. Thus began my first stint with disability, and the next chapter in my career.

I was determined to try again, and jumped back into teaching. This time it was in a new place, and with that came not only a tough job, but new doctors, new hospitals, new insurance, and the need to build a new support system. This is the part where the soundtrack turns ominous. The job was not a good fit and, yes, I admit that I bit off more than I could chew. I could also add another line to my list of lessons hopefully learned. The revolving hospitalizations continued, and after a year I was on Social Security Disability Insurance (SSDI).

My first time on SSDI was very difficult. I was sick, I was broke and I felt like CF had taken over my life and left me with no identity. As we all know, the process to obtaining benefits is challenging in its own right but especially so when you’re sick. That led to depression, more financial problems, and eventually to the very tough decision to move in with my mother. Things were already rough, but now I was hitting a new low.

As difficult as it was to pull up my boot straps, after two years of taking care of myself, eating and resting, I was able to start working part-time. This time I was working and navigating the crazy world of SSDI. A few years later, I was again working full time, and was back in New York with a strong support group. But, in keeping with the roller coaster metaphor, the up time was followed by a downside. I was sicker than I realized, and it took almost seven months to get back on my feet. This time I handled SSDI and my recovery better, and was much gentler on myself. While maybe not always smart, I was getting wiser. I began to understand, not just think, that I am not only about CF.

As it turns out, I’m back to teaching full time, and am also managing a busy life, a new relationship and going
to school two nights a week to get my California teaching credential. Being compliant with treatments is as difficult as ever, and I still struggle with the delicate balancing act. However, I love what I do, even though it takes a lot out of me. Things seem to be working well these days, and I haven’t been in the hospital for quite a while. But I’m not under any delusions and know that my health could turn at some point and I could find myself back on SSDI. I’ve chosen to take that risk, and know that it does come with a good number of rewards.

As I enter my fifth decade, I try to make smarter choices about my work and my life. My priorities have changed, and I deal with what comes up as a result of the choices I make. Yes, it’s good to have a little bit more money and not have to depend on public assistance. But I’ve also learned that I was wrong to think that being on disability meant that I was somehow not a productive member of society. Living with little to no money, particularly when many of my friends are making a good living, has been a real challenge for me and I have had to work through a lot of emotions on the issue. In the end, taking care of my health is a top priority.

I recently got some surprisingly good news about my health, despite the impression that my health was declining. Now the challenge is not getting caught up in the part of the roller coaster ride when your eyes are closed, the wind is in your hair, your adrenaline is pumping and it seems like you don’t have a care in the world. I know that I live with a real and demanding disability, and I’m getting better all the time at striking a balance. Yes, I’m enjoying the ride.

Rich is 40 and has CF. He is a Director of USACFA and writes the regularly featured “Unplugged”. His contact information is on page 2.

**BYRNES continued from page 7**

ranted only when proper planning, trails or navigation, and help is available.

Realistically, though, not everyone can find spiritual replenishment from being outdoors. When I had end-stage CF, I found little healing while gasping for air on top of a 3,000-foot mountain. Some people live in inhospitable climates (i.e., North Carolina in the summer) or flat terrain with limited access to public land (i.e. Nebraska). Some people have allergies or pale skin. Some live in concrete jungles and going into nature requires a major investment in time and money. Some people are mobility impaired (An aside: at the CFRI Retreat last year, we “hiked” on a paved trail, so that two people in wheelchairs could join us. It was a wonderful adaptation!). Some people don’t care. Some may prefer to curl up on the couch watching ‘Man vs. Wild.’ But I think there may be some unconscious, deep awakening of spirit within each of us when we enjoy potted plants, look up at the stars at night, or sit under a cherry tree in full bloom. I would dare anyone to wiggle their toes in the sand, gaze at a canopy of fall foliage, or soak up the sun at the beach, and see if those intimate connections with nature offer them spirit medicine. I wonder if something is aroused inside of you.

Coincidentally, the theme for the next CFRI Teen and Adult Retreat is “The Great Outdoors: A Breath of Fresh Air.” Come join us to experience California’s gorgeous nature; to heal your body, mind and spirit!  

Isabel Stenzel Byrnes, 37, is (obviously) from California. She has CF and had a bilateral lung transplant in February 2004. She invites you to share your spirit medicine.

**SUFIAN continued from page 5**

get SSI because their SSDI benefit is over the SSI amount in the state. A person who will not be eligible for SSI, due to SSDI amount, would not have a reason for having a special needs trust. In most states, a person over the age of 18 is not eligible for Medicaid in the state, unless the person is eligible for SSI.

I repeat this over and over to parents who still insist on paying an attorney $8000 to set up a special needs trust. This is unfortunate because, if their child is an adult and has worked enough to result in an SSDI check that is more than the SSI amount in the state, it is unlikely the adult child will need a special needs trust. I have repeated this phrase many times in this paragraph because I know it is difficult to understand. Some attorneys are looking for ways to make money. Make sure that you understand when a special needs trust is appropriate, before paying an attorney to set up a special needs trust.

4. I have received a large number of calls and e-mails about collection agencies and their efforts to collect debts that are due in part to medical debt. I will focus my next column on how to deal with collection efforts. Until then, remember that a collection agency is not a credit reporting agency. Having a debt go to collection does not mean it will show up on your credit report. Given the difficult economic times we face, many providers are stepping up collection efforts. If you do not have the money to pay a medical debt, make sure you tell the collection agent. No one should be sent to jail for inability to pay a medical debt. I hope that makes some of you feel better.

Beth is 42 and has CF. She is a Director of USACFA. Her contact information is on page 2. You may send her questions of a legal nature that are CF-related.
By Maggie Sheehan

"What do you want to be when you grow up?" It is such a simple question to the average five-year-old. "I want to be a ballerina! An astronaut! A tree!" At 21 years old, the question is still the same, just asked in a different way. "What kind of job are you looking for when you graduate?" Now, one would think this question has gotten easier. Quite the contrary; it is the most terrifying question one could ask these days. Yes, I am majoring in public relations (PR). And, yes, I selected that college major back when I was a senior in high school. Now where do I go for a job? Is it the right career path for me? Will my health allow me to have a full time job? Do I go straight to part time? Was my degree a waste of time? So many questions and so little time to decide.

At the ripe age of ten, I was convinced I was going to be a doctor and help kids with CF. I now laugh when I think about that. I was never cut out to be a doctor; heck, already I spend 24/7 taking care of myself. How could I ever give enough of myself to other patients?

Human beings are creatures of habit and we do what we know. Most people with CF know medical jargon, know their disease very well, know the hospital system, and know and understand healthcare as a whole. So the question then is, why not go into something revolving around a hospital or with sick people? My doctor gave me the best advice I could ever ask for. She was telling me to find my own path without thinking about my disease, the hospital or the healthcare system.

I considered teaching next but realized being away from my class while in the hospital was going to be too difficult. Later I wondered how I would like working behind a desk, in front of a computer, dressed up, nine-to-five every day. It sounded boring and monotonous. I came to the conclusion the one thing I knew a lot about was fundraising. It was my family's passion, and it definitely made me feel good inside knowing I was helping others without being in direct, physical contact with them.

Eureka! I wanted to work in the non-profit sector! PR was going to be the perfect fit for me. It is all about communicating with others and getting someone's message out to the media in a positive way.

I pursued a part-time position at Children's Memorial Hospital Foundation, in the Major Gifts department. Don't be alarmed. My office is in a building separate from the main hospital. This job is perfect for me because I learn what it means to give back. I get to work with people who want to donate to a specific cause within the hospital, and most of these are families with children who have been treated by the staff at Children's Memorial Hospital.

I know it sounds as if this job is perfect, but I still have many questions about whether it will fit in my future career path. Where will I end up after graduation? What kind of challenges will my health put in front of me? And is there really a perfect job/career for any individual living with a chronic illness? I don't have these answers. I just know what is best for me at this time.

I do recommend having an open dialogue with your doctor about your career path and reaching out to the CF community for suggestions. Maybe being a nurse in a hospital is right up your alley. Maybe being the kindergarten teacher is perfect for you, or maybe not working at all and taking care of yourself is your full time job (don't you wish we got paid for that last one?).

Whatever you choose or whatever your body allows you to do is what you should do. What is important is that you feel fulfilled. I hope this can help anyone just starting college or looking to go back to school for a new career. If any of you have answers to my life-pondering questions, you know where to reach me. Perhaps I will decide to just be a tree! Kids have a lot of good insight anyway!

Maggie is 21 and has CF. She is a Director of USACFA. Her contact information is on page 2.
A Day In A Life

We step onto the stage and instantly I’m sweating from the blinding lights.
The weight of the horn around my neck will be unrelenting.

Maybe the warmth will loosen my back up; but that’s wishful thinking ... I know the pain will only get worse as the night progresses. “Funny,” I think “to be worried about my back after I just spent 90 minutes spittin’ and hackin’ my guts out just so I can breathe enough to even do this!” “Interesting, how my brain discounts all that stuff ....”

“1,2,3,4” ... the band comes to life.
I hear the familiar ‘clicka-clicka BOOM click’ from the drums accompanied by the steady pulse of the bass.
The piano kicks in with a percussive carpet of chords.
From my spot on stage I can’t see them but I don’t need to. Hearing them is all that matters.

What an absolute thrill it is!
Familiar and comfortable and yet still as exciting as my first gig.
This wonderful music.
It’s my passion,
My best friend,
My identity,
My LIFE,
As well as my profession.
Through it I’m privileged to experience a slice of the incredible splendor that life offers us... the magnificent beauty that IS life.

“I’m the luckiest cat in the world” I think as I gather up my breath and start playing. And you know, I forgot all about that backache for a while....

– Scott Petersen

“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...

MAGGIE SURROUNDED BY HER FAMILY IN THE HOSPITAL LAST SUMMER. FROM LEFT TO RIGHT: KERRY SHEEHAN (MOM), MAGGIE SHEEHAN, STEVEN SHEEHAN (YOUNGER BROTHER), ED SHEEHAN (FATHER).

PAUL FELD RELAXING AT HOME.

ANDREA EISENMAN AT HER COMPUTER.

RICH DENAGEL

ISA STENZEL BYRNES ENJOYING THE GREAT OUTDOORS.
BOOK REVIEW

Tara and The Place of Irish Kings

By Gail Joseph Owen
With Vanessa Davis Griggs
ISBN: 978-0-9798213-0-1
Reviewed by Kathy Russell

Tara and The Place of Irish Kings is a book about a young woman who had CF and wanted to write a book about her life. Sadly, she died before she was able to do it. So, her mother compiled her writings and put them together with the memories and reminiscences of others, to fulfill Tara's wish.

The book begins with Tara’s writings about having CF. It goes on through her family history and all of her life. Her mother uses Tara’s many diaries and journals to create an interesting read. This is the story of a life that lasted 28 years and was full, even though she had CF.

The book tells of Tara’s early years, high school and college life, as well as trips that she took. She traveled to Europe and several places in the USA. She held a job and did many things that others only dream of. She even bought a shiny new convertible and a house. She had loves and disappointments. Tara was willing to take some risks, in order to do the things she wanted to.

When her doctors told her that she needed lung transplants, she went through the work-up. However, when lungs became available, she decided that the surgery wasn’t for her. She lived another four years.

If you are looking for a pleasant book to read, that has a connection with CF, this may be what you’ve been seeking. At 192 pages, in soft cover format, it is easily tucked into one’s bag for travel or for those long days of clinic visits.

This book may be ordered at: www.SunshinePublishingInc.com or at any bookseller.

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affects key measures of how well the protein is functioning. The trial is expected to enroll approximately 90 patients with the Delta F508 mutation of CF, the most common mutation in CF patients.
http://tinyurl.com/dfycfu

TREATMENTS AND INTERVENTIONS


Chronic infection of the airways with P. aeruginosa is the leading cause of morbidity and mortality in the majority of CF patients. Novel strategies to fight the infection may be developed by interfering with the bacterial attachment to the airway epithelium. P. aeruginosa produces two lectins, carbohydrate binding proteins, designated P. aeruginosa lectin I (PA-I or Lec A) and II (PA-II or Lec B). The first one is specific for galactose, the second for fucose. Both lectins are used in two clever ways to facilitate its pathogenicity. The two lectins bind to the sugar coat of the surface lining epithelia and stop the cilia beating. By adding simple sugars, this attachment can be blocked. The sugar inhalation was well tolerated and no adverse side effects were observed. Inhalation significantly decreased P. aeruginosa in sputum. No change in lung function measurements was observed. Thus, inhalation of simple sugars is a safe and effective measure to reduce the P. aeruginosa counts in CF patients. This may provide an alternative therapeutic approach to treat infection with P. aeruginosa.
http://www.medsci.org/v05p0371.htm

Stabilization of Lung Function and Clinical Symptoms in a Patient with Cystic Fibrosis (CF) After Institution of Infliximab: A Monoclonal Antibody that Binds Tumor Necrosis Factor alpha. Brian Caserly and Walter Donat. Lung. Published online: 27 February 2009

The most characteristic feature of airway inflammation in cystic fibrosis

Continued on page 21
Yes, spring has arrived here in Connecticut and it feels grand. At the time of this publication, the spring flowers are coming into bloom. The old magnolia in our front yard has tiny pink buds. Our garden is beginning to come alive again with signs of new growth emerging. I always consider it a miracle seeing that our bulbs survived the harsh winter, despite the skunks, deer, squirrels and other creatures that think this the best buffet ever. Nature is gracing us with gifts every day.

A Winter Sunset

Winter sunsets are my favorite. The colors in these sunsets seem more intense. Is it due to cold weather - temperature at that time of day was 23 degrees? Perhaps it is because I am used to looking at muted colors - brown leaves on the ground, dull looking grass, stark trees, bushes, a sense of grey everywhere, etc. The evergreens offer relief, as does the light throughout the days.

On January 4, I was driving on Route 1 in Norwalk, CT around 4 pm. Looking west, it was easy to see the beginnings of a spectacular sunset. Problem was that there was no place on Route 1 that offered a good view. Buildings, telephone poles, miles of wires, and cars all created a blotch on the landscape. Once home, I grabbed the tripod, (camera was already in the car) and headed out to the nearest location to capture the sky’s majestic colors.

Like the early morning light, light in the late afternoon changes rapidly, so act fast. There was no time to drive to a higher elevation in town. The local high school up the road was the spot. The tripod was set up on the soccer field, fully extended to max height to enable me to shoot above the Nursing Home’s parking lot, thus the loss of depth from the snow on the field. The sky was what was important but so was the foreground of trees for the contrast. The small evergreen framed by trees surrounding it caught my attention. By now the colors from the setting
sun had intensified. When using a slow shutter speed, it is better to use the camera’s self-timer or a remote control to avoid any camera shake when pressing the shutter.

Camera Info: Nikon D90 taken on January 4, 2009, at 5pm. at 1/8 sec., F13, ISO 800, 18-200mm lens at 82 mm.

A Close Encounter With A Crocus

I’ve given up trying to grow crocuses over the years. Year after year, no sooner had the blooms appeared, than they would get pruned by our wildlife gourmards. There are hundreds of crocuses in this town alone, dotting the roads, in front of stores and certainly in gardens or fields.

Last Sunday at the Nature Center, I discovered three lonely crocuses tucked away in the meadow near the Cattails. The white with lilac stripes are one of my favorite varieties. Bonus: one crocus had a fully opened petal, allowing a clear view of the three stamens, a great macro (close-up shot). How I wished I had my tripod and macro lens with me. The only way to get a “pseudo” close-up was to extend my telephoto lens to the maximum 200 mm and to get as close to the crocus as possible. Due to the afternoon light, the ISO was increased to allow for a greater depth of field. Photo was cropped in CS3.

Camera data: Nikon D90 taken on March 28, 2009, at 1/250 second, F16, ISO 1,000 with 18-200 mm lens at 200 mm.

Tulip Heaven

Longwood Gardens is one of the country’s most noted botanical gardens. It is located in Kennett Square, PA, about 30 miles from Philadelphia. Look it up on the web at www.longwoodgardens.org. Since our first visit, with Mum back in April 2006, Bill and I have been back four times. Late April through May is stunningly beautiful.

On April 29, 2006, Bill, Mum and I drove down from Connecticut, arriving at Longwood Gardens in the late afternoon. The light was spectacular. One of the center gardens has a 600 foot walkway. In the spring, this walkway is bordered by a spectacular showcase of tulips, arranged by color with an under-planting of pansies and other annuals. The spring bulbs are pulled up after the growing season. In the fall the beds are replanted with 100,000 new tulip bulbs. Longwood does recycle some of their tulips and gives others away.

Finding the photograph...Most professional photographers agree that it is always better to familiarize yourself with the subject and area before taking the camera out. Look at the angles, is the shot from a bird’s eye view or worm’s eye, the direction of the light, look for lines, horizontal, verticals, diagonals, circles, squares, color patterns, etc. A one-eye squint enables you to see color and texture better.

The gardens were closing in 15 minutes so that there wasn’t much time to do all of these things. I knew that if I walked behind the garden beds, I could somewhat obscure the paved walkway between the borders and have the sun backlight the flowers for a more glowing, interesting look. In public gardens it is often hard to avoid people walking through the frame. However, in this case, I wanted to show interest and scale, so I waited for these two women to walk out of the back center towards the left side. Patience is a virtue.

Camera Data: Nikon D100 taken on April 29, 2006, at 1/160 second, F11, ISO 200 with 18-70 mm lens at 70 mm.

Until next time, happy shooting and remember to delight in nature’s gifts. ▲

Pamie is 55 and has CF. She was a Director of USACFA for several years. You may contact her through cfroundtable@usacfa.com.

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(CF) is the persistent infiltration of massive numbers of neutrophils. Although inflammation is primarily a protective response to injury, it has the potential to cause considerable harm when it is excessive. Recent recognition of the prominent role of inflammation has prompted the investigation of treatments designed to control inflammation in the CF lung. We report a 35-year-old man with abrupt stabilization of his rapidly progressive CF and forced expiratory volume (FEV₁) after starting infliximab for his rheumatoid arthritis. This effect was sustained for 8 years while continuing to use twice-monthly infliximab.

http://www.springerlink.com/content/89582353mxq4786p/


Excess mucus in the lungs of people with cystic fibrosis can lead to constant infection and inflammation. This damages the airways and results in a progressive loss in lung function. Chest physiotherapy attempts to clear excess mucus from the lungs of people with cystic fibrosis. There are a number of different methods used on their own or in combination with each other - manual techniques, breathing techniques and mechanical devices. Oscillating devices generate pressure within or outside of the body to move the mucus. Thirty trials (708 people) of different devices were reviewed. There was no clear evidence that oscillation was a more or less effective intervention overall than other forms of physiotherapy. More adequately-powered long-term randomised controlled trials are needed. Physiotherapists should consider the needs of their patients and recommend the most suitable method

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Ever since grammar school, I knew that I wanted to be a doctor for the simple reason that I wanted to help others, especially those like my closest sibling, my sister, who at an early age exhibited persistent health problems. In my young mind, a doctor was the best way to accomplish that. Looking back, I realize that I had no idea what entering this profession really entailed. That probably was a good thing - so that the idea could germinate and become deeply ingrained in my being. It was a good decision.

By high school I was ready to divulge my career choice to others and, surprisingly, discouragement was everywhere and it didn’t have anything to do with cystic fibrosis. That’s because I was diagnosed with CF as an adult, after I had already completed my training and had become a full-fledged doctor.

Why such discouragement by so many different people? I’m not sure because, really, I believe I was perceived as an upstanding individual (at that time anyway). Did the inane comments matter to me? Sure, at first they were confusing and intimidating; however, as time passed, these comments served to inspire and encourage, and, ultimately, to prove to myself (and anyone else who was wondering) that I was up to the task at hand. Aside from the many disheartening words I received, I can only imagine what less-than-inspiring conversations would have occurred if the CF had been diagnosed earlier.

Here is just a sampling of some of the finer lines thrown my way and, mostly, from non-medical individuals. The very first was pointing out that I was scared of blood, even when it came from smashed spiders, so how could I handle drawing blood or something worse? Good point. Next was the “Well, it takes a lot of work, you can’t have a family, you’ll probably get divorced, you won’t have a life…” This might work on someone who wasn’t passionate about his or her career. Then there was the cliché, “Well, you’re a woman and it’s harder for women because it’s a male-dominated field…” blah, blah, blah– as if I hadn’t heard that many, many times before. What’s amazing is that I hadn’t heard anything like this from my five brothers who, while they teased and taunted about everything else, didn’t think twice about my becoming a doctor. (Come to think of it, they may not have thought once about it either.)

The next attempt to unnerve had to do with an obvious physical appearance – no, not the fact that I have two eyes, ears and one nose (although I was surprised that some tactic involving that wasn’t tried), but that I’m Hispanic – full-blooded, 100%, except that, at the time, I hadn’t learned fluent Spanish (long story). In the eyes of a befuddled few, being in between the full-blooded appearance, and yet not fully entrenched in what “they” believed was the stereotypical Mariachi-loving, Spanish-speaking culture made me feel like I was some sort of imposter, pulling a fast one. Turned out that my “Spanglish” (the only Spanish I knew, initially) created lots of entertainment with Spanish-speaking patients who eventually served as my teachers to become fluent in Spanish.

One of my favorite disparaging remarks was made by an old high school friend, who asked about my current work situation. After learning that I was in medical school, he said, “Well, I never pegged you for a doctor. You don’t look like one.” I guess I was just too wild and crazy in high school. I was curious, however, as to what a doctor should look like, and I’m still not sure.

Coming from a large family of eight siblings provided a training ground that taught me to let comments like these bounce off me or, at least, not take them so seriously. Most of the time, I was successful. When I wasn’t, I could turn to my parents, siblings, friends, or later, my husband-to-be for the necessary encouragement. I was, of course, determined to proceed with my medical career with no holds barred.

As my symptoms of CF progressed, from repeated sinus infections in high school, breathlessness in college, and “asthma”, pneumonia and lung collapses in medical school and beyond, the most common deflating
response I received was, “Physician, heal thyself.” As if… Despite these remarks that only “skim the surface” I succeeded in becoming a doctor, still not knowing that CF was lurking; however, even with a negative sweat chloride, I was still highly suspicious but had no way to prove it. Five years after finishing medical school, genetic testing for CF was in common use. Through genetic testing I diagnosed myself and three other siblings (even longer story) and began the beautiful road to feeling better by finally receiving the correct medications that could treat and prevent my CF symptoms.

I could end it right here, but then I would be telling you only a half-truth, because my biggest career decision came 15 years after becoming a physician. As the CF progressed, I found myself missing more workdays with more frequent hospitalizations, more medications and overwhelming fatigue. Working part-time certainly did not alleviate the progression. The sudden passing away of my “nearly twin” sister (many relatives couldn’t tell us apart and we were very close) from CF two years prior had planted a seed and really forced me to consider the ultimate decision to stop working (still difficult to write those words). We had considered the symptoms of CF simply a nuisance for so long that the realization finally hit that this disease is deadly serious and can no longer be dismissed.

After many trials of part-time weeks of four, then three working days, etc, it became apparent that I could not even guarantee that I would show up a single day each week. My health was declining and I couldn’t even work one day?! It seems fairly obvious now in hindsight, but at the time, I felt like I was throwing away all those years of learning, practicing, and teaching. I wasn’t ready to leave my brilliant colleagues, magnificent staff, not to mention my sweet patients (who didn’t care when I wore a face-mask). I deluded and forced myself into returning full-time, still with the no-holds-barred attitude which had carried me through so much of my medical training; and despite the obvious, convinced that it was all psychological.

The event that finally did the trick came from a pulmonologist covering the weekend (not my regular one) while I was hospitalized. We had worked briefly together on a committee so I guess he felt he could be straightforward, no sugar coating. He stated that with my CT scan results and rapid rate of lung function decline, transplantation would probably be necessary in five years. Being diagnosed so late, I never dreamed that transplantation would be a necessity. Thoughts flooded my mind (in addition to tears) of my three children and the grandchildren yet to come, my life with my husband of 22 years and how, or if, we would be spending our “golden years” together. Delaying transplantation became my new mission and the straw that broke this camel’s back. Although I was upset at him for laying it on me so bluntly, I’m grateful now that the “T” word brought me back to reality and gave me the courage to let go of working.

Knowing what I have learned about CF and being a doctor and the combination, would I have changed anything? Certainly not! Medicine has always been my passion (when it comes to careers) and I like to believe that I would not have changed any part of it. Little did I know, at that time, that medicine – taking medicine that is – would become my next crime of passion. Two years would pass, after leaving my job, before significant improvement was felt. And for a majority of that time I, interestingly, became worse before getting better.

When the idea of becoming a physician was still swirling around in my childhood, would additional criticisms regarding CF and the potential health decline (which no one can predict 100%, even less so when the disease is “young”, by the way) have changed my mind? Again, I like to believe that it would not have made an iota of difference, and now I certainly would encourage everyone with CF to pursue whatever career path they desire.

As I did, eventually, you’ll overcome any fears you might have. For instance, instead of drawing blood with eyes closed to avoid the unsightly blood, I highly recommend watching what you’re doing during phlebotomy and, of course, would you believe it’s much easier and safer for the patient, too! Also, it turns out there are large numbers of marvelous women in medicine of all different colors, sizes and shapes, with and without families and children, who make it work and have a life outside of medicine, so no worries there.

In addition to learning how to scoff at discouragement, intimate knowledge within the field of medicine has provided and continues to provide enormous benefits to my health and that of others I am still able to help. Although I miss the hands-on interaction of patient care immensely, the doctoring still occurs, albeit a little less directly, and this fits my current lifestyle. Now, I am able to volunteer my time (from home, mostly) for different medical, CF and non-CF related functions, fundraisers, periodicals and advocacy groups. But mostly, I am able to spend time with my husband, children and other close friends; and, most importantly, care for myself the right way, no excuses, no holds barred! ▲

Jeanie is 46 years old and has CF. She is a physician. She lives with her husband, John, and three teenagers in Los Angeles.
Making Career Choices with CF

Career and Retirement Choices

By Andrea Eisenman

Once I made the decision to go into the graphic arts field and had worked for nearly 13 years, I had to make the decision to retire at 33. As a child, I was always drawing and doodling. My parents and grandparents had been giving numerous drawings and everyone's refrigerator door was covered with my “masterpieces” from about age two. It was no surprise that I went to an art high school in New York City and the next logical step was an art college. I went to SUNY Purchase as it was close enough to the city where I grew up, and also to my doctors, but far enough that I could live at school and try my hand at independence from home.

In college, I was pushed in the direction of graphics by my dad who knew the field through being a printing salesman. In his capacity as a salesman, he worked with many art directors and thought this could be a rewarding career for his daughter. Since I was studying painting at school, he told me design was a good way to support myself, rather than being a poverty-stricken painter. I changed majors and realized I really enjoyed turning text and images into something pleasing to look at. He felt I could get a job at a company and get the needed health insurance for my cystic fibrosis. I had not thought it through, but he was right. I started out freelancing but then got a job in magazine publishing. I received great health benefits and decent work hours: 9-5.

As my health deteriorated over the years, and I changed jobs a few times, I had to face the reality that I could not work for the rest of my life, unless I wanted my life to be severely shortened. It was recommended at this time that I get listed for a bilateral lung transplant. Not a shock – I knew it was my only hope. I got listed and then really started to have trouble maintaining my life, if you can call it that. I went on a disability leave, at first for three months. I thought that if I could just take some time away from work, I would improve my lung function if all I did was take care of myself. I was wrong. I got sicker and had to take permanent disability leave within a year.

I have been fully retired since 1998. At that time, I could barely do anything except therapy and IVs and wait for my transplant. My second chance at life came in April 2000. It was the greatest gift that saved my life. My transplant transformed me from someone barely alive and needing full-time oxygen to someone who could finally breathe without coughing. I never expected to feel the way I did. I was able to do exercise and do things I had not done since I was 12 years old. But I knew that these lungs came with a price and responsibility.

I knew that I had to be compliant and do whatever the doctors told me to do. So, of course, I took my medications, exercised and after talking with my pulmonologist, Dr. Larry Schulman, decided not to return to work. Many reasons influenced his and my decision. Mainly, people in the work place are sick a lot and I would catch whatever went around as I did prior to my transplant. This would compromise my newly-transplanted lungs. And being immuno-suppressed would only exacerbate this situation. Secondly, I would not have the time to care for myself properly if I returned to work full-time: eating right, exercise, resting, managing my diabetes, chest PT (I still did this for about two years after transplant), and just living my life.

Quitting work was not an easy decision, but it was the right one. I am almost nine years post-transplant and I know that if I had gone back to work, I would not be writing this article today. What I had to learn was to take care of myself properly but also rebuild my life without paid work. Receiving healthy new lungs is a rarity and they are harder to maintain than some other organ transplants: for the reason that they are your air filter and whatever is in the environment will affect them. Other organs are less sensitive to pollutants, allergens, bacteria, viruses, infections, etc. If not working full-time was the price for living a healthy life, I was willing to pay.

There was a period of doubt about what I would do with myself to keep busy. Well, it had taken some time but early on, Kathy Russell reached out to me to see if I would be interested in joining the board of USACFA. I jumped at the chance and was able to offer my graphic skills to CF Roundtable, and a few years later help to create the website. I also found out about the New York Organ Donor Network (NYODN) and the transplant games through a fellow recipient. I became a volunteer with NYODN, where I help out about once a week.

It is very satisfying to give back by speaking about my transplant experience to educate others on organ donation, so that others may receive a life-saving transplant, too. I also help in the office with computer work and create fun invitations for their parties. Participation in the US Transplant Games is another way to
educate the public that organ donation works. I participated in 2004 and 2006. And I design two other CF newsletters as well.

Getting a dog has kept me busy with walks and meeting people in the park. See my previous article on Love, Dating and Marriage in the Winter 2009 CF Roundtable where I write about meeting my husband in the dog run. I am in the process of making a documentary about secrecy and disease (CF) in the Orthodox Jewish community. And then there are days when I just sleep and read most of the day away. All of these things keep me busy, sometimes busier than a full-time job. But I know that if at any time I cannot do it, since I am a volunteer, my health can come first.

Even though I do not work for pay my life is satisfying. But the problem arises for me when people ask, “What do you do?” “Are you working?” I try to assess who is asking me. Is it a medical person? Will they understand when I tell them I am on disability? Are they just asking to be polite? Then I answer accordingly.

In the beginning, after my transplant, I looked well enough to work. But looking and feeling are two different things, as anyone with CF knows. After going through the agony of deciding to be on disability, when asked, I told people that I was disabled. Here are some of the responses: “You sure look like you are OK to me.” “There doesn’t seem to be anything wrong with you, why can’t you work?” “Cheating the system, eh?” My family and friends understood, especially seeing what I had been through prior to transplant. But people’s reactions upset me as, I guess I had the guilt of not working, working against me. It has taken me years to realize that I can contribute in my own way without officially working.

So now, when asked what I do, I take a moment to think, “Is this someone I will be friendly with in the future or is this a one-time meeting? Do I need to tell this person I am disabled or can I tell them that I am a graphic designer and do pro-bono work for non-profit organizations?” Both are true to some extent. I sometimes tell a little of both and when I know them better, tell them more, if they want to know about my transplant and CF.

As a person with CF and a transplant, I know that there are no guarantees about survival rates and life expectancy. So I do my best to stay healthy by not working, keeping to an exercise regimen, eating healthy foods and staying motivated by keeping active in volunteer activities. I am thankful for my second chance at life and I try to maintain my lungs at all costs. I hope to never be as sick as I was prior to transplant but, if it does happen, I will know that I did everything in my power to prevent it by the decisions I have made. ▲

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.
s a high school senior freshly diagnosed with cystic fibrosis, building a long-term job career was not in the forefront of my priorities. I had just been delivered the message that my life span would be short and that my first concern should be my health and just after that, insurance coverage for my healthcare – as life was about to get expensive. As a practical and mostly logical thinking person, I led myself to believe that the best medical insurance coverage I could get would be from a large employer. This would probably lead to the least expensive coverage as well.

When I was diagnosed, I was already working for one of the largest employers in the country, McDonnell-Douglas, and I was working in their hospital services division. While on the surface that sounded good, I was working 3rd shift unloading paper off trucks to be used in the printing room of the large mainframe computers. It was tough, physical work for a 135 pound kid, and the hours left much to be desired. It did, however, get me in the door for both a healthcare and an I/T career.

From McDonnell-Douglas, I went to work for a local supermarket in St. Louis, called Schnucks. They were also the largest grocer in town, and I got on as a computer operator on second shift. They had a good medical plan and treated me very well. I got a lot of “on the job” training and, after three years, was promoted to their programming staff. The job and people were fantastic, but their pay was somewhat less than competitive at the time, and my young family needed more. So after five years at Schnucks, I moved on to other I/T opportunities with several large, good

foremost, its premier hospital was less than one mile from my home, so I could walk to work if necessary. Second, they had a great pulmonary staff to help me care for my CF. While the pay wasn’t top-scale, the medical benefits were; and that was becoming more important to me than pay anyway, as healthcare costs were taking more and more of the pay I took home. Finally, its I/T staff had only

about a dozen people there, and I knew if I did good, solid work, it would be recognized by the management of our organization. It was also an indoor desk job, so the environment was very helpful to my long-term health concerns.

As a practical and mostly logical thinking person, I led myself to believe that the best medical insurance coverage I could get would be from a large employer.
of airway clearance for the individual.  
http://www.cochrane.org/reviews/en/ab006842.html


Cystic fibrosis is a genetic disorder which mainly affects the lungs. Chest infections recur in people with cystic fibrosis due to a build up of thick sputum (phlegm) in the air passages. Several treatments, including thiol derivatives, aim to loosen this sputum and so improve lung function and reduce the frequency of chest infections. Thiol derivatives may be either nebulized (breathed in) or oral (by mouth). They have been shown to help in other lung conditions, such as chronic obstructive pulmonary disease. This review aims to find out if there is enough evidence to recommend the nebulized or oral thiol derivatives for people with cystic fibrosis. Eight trials were included; three assessed the effect of nebulized thiol derivatives. Of the nebulized studies, one compared 20% n-acetylcysteine to 2% n-acetylcysteine; another compared sodium-2-mercaptoethane sulphonate to 7% hypertonic saline; and the other compared glutathione to 4% hypertonic saline. Nebulized thiol derivatives were generally well-tolerated with no major adverse effects. However they showed no significant improvements in any of the outcome measures. The studies included in the review did not provide any evidence that nebulized or oral thiol derivatives were either beneficial or harmful to people with cystic fibrosis. Further research investigating the effects of thiol derivatives in people with cystic fibrosis is required before their use can be recommended.  
http://www.cochrane.org/reviews/en/ab007168.html


Corrected Proof Reports indicate that nutritional and respiratory decline occur up to four years prior to diagnosis of cystic fibrosis related diabetes (CFRD). Our aim was to establish whether intensive nutritional intervention prevents pre-diabetic nutritional decline in an adult population with CFRD. Prediabetic nutritional decline is not inevitable in adults with CFRD, but is influenced by age of onset. In the group overall, those with CFRD are more likely to require ETF [enteral tube feeding] from 2 years prior to diagnosis. Despite intensive nutritional intervention, patients who continue to grow throughout the pre-diabetic years, show a level of nutritional decline absent in older adults.  
http://tinyurl.com/avxnsx

LUNG TRANSPLANTATION


As short- and long-term survival rates for lung transplantation continue to improve, and as more lung transplantations are occurring with each year, a multitude of medical complications are encountered by the

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How is a career choice related to wellness? First, when I write about wellness with CF, I am not simply talking about physical health and wellness, but also emotional well being...a sense of contentment and fulfillment. Many things are related to this sense of well-being and, fortunately, most have little to do with physical health.

I've been reading and thinking a lot about happiness lately. If you've read my column before, you probably know that I find the field of positive psychology fascinating. Essentially, it is the study of what causes people to be happy and to live rich and fulfilling lives. Happiness is a popular topic these days. You see happiness “secrets” revealed on book and magazine covers, on PBS specials, on happiness blogs, websites...you name it.

My purpose is to mine the fields of positive psychology and happiness research to come up with scientifically validated ways to improve the subjective well-being of people with chronic illness and, of course, cystic fibrosis is a perfect example.

So what does this have to do with career choice?

The research tells us that one of the most important elements of living a good, fulfilling life is the ability to use your strengths in a manner that serves a purpose that is larger than yourself...one that you believe in deeply and that aligns with your core values. Those people for whom work is a calling feel the most fulfilled. And there is a strong positive correlation between happiness and using your strengths every day. Wouldn’t it be awesome if you could do that and get paid? You can...and you should strive to do just that.

We all have strengths, and I’m sure you have a very good idea of what your particular strengths are. It has only been a recent discovery that people who are the happiest immerse themselves in using their strengths rather than using their finite amount of time and energy to “shore up” their weaknesses. I believe that the very first thing to take into account when deciding a career path is, “What are you good at?” Notice, I didn’t say, “What do you think you can handle, given CF?”

If you want to try a fun and often revealing exercise, take the VIA Signature Strengths Survey at http://www.authentichappiness.org. This is a series of 240 multiple-choice questions (it takes 45 minutes or so), and when you are done, you will immediately see which are your top five (or Signature) Strengths. I thought I knew what my results would be, and I was close, but there were some that completely blew me away. You will also get an interesting perspective on your own strengths by asking those that know you well what qualities they most admire in you. Finally, make your own list of things you love to do and that you know you do well. Try to narrow this down into five or six things in which you take great pride and satisfaction. Combining all of these methods will give you a very accurate map of the kind of career you will find most fulfilling. It will be the one(s) where you see the need and the opportunity for these strengths at every turn.

Looking back to my decision to go to medical school to ultimately “cure cystic fibrosis”, I realize that I could have used this advice. When one thinks of a good researcher, strengths like the capacity to love and be loved, humor, zest, curiosity and love of learning, and hope/optimism/future mindedness (my top five) are not the ones that first come to mind. A great researcher would show strengths like industry, diligence, critical thinking, caution, judgment, ingenuity, and leadership (not even close to my top five). While my passion was in the right place (curing CF), my strengths were not suited well to this career decision.

Now, this didn’t turn out all bad. I loved going to medical school. My love...
of learning and curiosity strengths were force-fed every day for 10 years of training. I got to tell great pathology jokes. But let’s just say that sitting around diagnosing cancer (after the intellectual thrill of figuring it out) did nothing for my zest, my hope and my optimism. And who loves their pathologist? Was I happy? Not so much. When it came time to retire to take care of my children and myself, I went through a slight existential crisis (well if I’m not a doctor, then who am I?) but then settled into post-physician existence quite happily.

Now I am entrenched in career number two, coaching and training wellness to people who, like myself, live in less than perfect bodies that often require care and attention above and beyond the norm. I use my strengths in a much more effective and ongoing way, and I am appreciated for them more than I ever was sitting at my microscope. And I care deeply about the meaning and usefulness of my work. I feel that I am doing what I “should” be doing. Given that I have always had a passion for fitness, nutrition and stress management, I get a kick out of sharing this with other people, and love learning even more about these topics. This leads to a sense of fulfillment and contentment that I didn’t feel as a surgical pathologist.

So what can you learn from this story? First, it pays to learn your strengths and give them serious consideration when choosing your career. The same goes for following your passions, and figuring out a way to merge your core values with your daily job. But, finally, what you can learn from this story is that sometimes, despite your best intention, your “dream” job takes awhile to manifest.

You may decide on one path, and find out later that it doesn’t work out as well as you had hoped. Or you may love what you do for a time, and then physical challenges may force you to be more attentive to your own health needs than that particular job allows. All of this happens…to everyone, really. When you are first deciding on a career, in your early twenties, it may seem like you only get one chance and you can’t afford to mess it up.

You might be making yourself crazy by thinking, “I can do this now, but what if I get sick?” Sure, be practical. You probably shouldn’t become a firefighter! But why paralyze yourself by imagining what may happen in the future?

Barack Obama said something in his inaugural address that struck me (actually, most of what he said struck me…but this I remember). He said he rejected the notion that, as a nation, we couldn’t both follow our values and be safe. To paraphrase him, I reject the notion that as people with cystic fibrosis, we can’t both follow our passions and be well.

Your career is obviously a very personal choice…one that you will live with day in and day out. Most people you talk to will give you practical advice: Think about your health. How stressed will you be? Will you be able to care for yourself appropriately? How healthy are you now? What can you do now?

These are obviously important to consider. But remember also to consider the following: What are your strengths? What are your values? Is it more important to you to work your tail off doing what you love, or to work at a less stressful job so that you can place more energy and attention on your own health and family? These aren’t “right” or “wrong” questions. They are just questions…to which only you know the answers. ▲

Julie, is 48 and is a physician who has CF. You may direct your questions regarding CF-related health issues to her at: jdesch@usacfa.org.
I've been employed as a genetic counselor working at a Prenatal Diagnosis Unit in a major academic hospital for over ten years. In this role, I often counsel pregnant women about their risks of having a baby born with a genetic problem or birth defect, and offer them appropriate testing options – either carrier testing or, prenatal testing.

As a person with CF, I often wonder how I can relate to my pregnant patients, since I have never been pregnant nor do I intend to ever become a mother. But after my double lung transplant in 2000 and subsequent repeat transplant in 2007, I’ve found a way to relate to my normal, healthy pregnant patients by finding parallels between the transplant experience and the pregnancy experience.

Here are my observations. Perhaps some of you can relate.

There is a waiting time in pregnancy and with transplant, a time where, in most cases, the body undergoes change. In that waiting time, there is anticipation, preparation, fear, anxiety and the need to take the best care of one’s health to prepare for “delivery.” Nutrition, exercise and monitoring for complications are essential at this time. Although transplant does not have a definitive due date, the wait does have a finite time, a “gestational” period, if you will, to prepare. There are fears of the unknown, medical visits and tests that need to be done to prepare for both. There is a commitment that comes with being listed and getting pregnant – a commitment to change, to hope and to making the promise of taking care of something or someone forever.

When the call for transplant finally comes, I think of it like going into labor. There is a rush of adrenaline and, possibly, a frantic run around the house to grab the suitcase before heading to the hospital. There are phone calls to loved ones to be made and e-mail blasts to send. Upon arriving, there is the welcomed excitement of the hospital staff that is ready to prep you for your “delivery.” Although dry runs are more common in transplant (where the lungs can be found not suitable for surgery), they can still happen, albeit rarely, for some pregnant women.

The big difference between transplant and labor is that we get to get knocked out for the rebirth of our lungs. Pregnant women, unfortunately, have to labor through the process of delivery. But after surgery, both of us usually get epidurals and many pain medications. For lung transplant there is that strange awakening, a period of drugged-up stupor and disbelief that lasts a bit longer than that of an average new mother. Of course, the recovery for transplant is harder.

Just as there is a post-partum period, there is also a post-surgery period for those of us going through lung transplants. There is the potential for post-rebirth depression, and for physical changes such as facial changes, puffy ankles, enlarged breasts (for some women having transplant) and hormonal changes (due to the meds). Most importantly, priorities change. In most new mothers their baby becomes their number one priority. In most lung transplant recipients, their lungs become their number one priority. It is our new child - to be cared for, nurtured and loved.

Our lungs are to be celebrated and embraced as miraculous as the birth of a baby (if not more).
or rejecting their young during times of desperate sleep deprivation. In doing so, some of us undergo a spiritual transformation as we enter a new phase of life, growing in unconditional love for others - be it our child or our donor family’s gift. In both cases, the miracle of life is transformative, illuminating and awe inspiring.

The anxiety of how our “baby” will grow and what the future holds will continue for new moms and lung transplant recipients alike. All we can do is take care of our baby as best as possible, and hope and pray for the best. For some, luck plays a big role.

Many pregnant women state that their bodies are never the same after giving birth. The same goes for transplant. There is weight gain, changes in motivation, body image and definition, and even habits. Many transplant recipients also report that almost every part of their body, mind and spirit changed after their surgery, for the most part for the better.

As our “baby” grows and develops, we find the potential is great for growth, adventure and admiration. We embrace those firsts - first walks, runs, trips without oxygen - just as new moms embrace the first smiles, the first steps, the first “Ma-ma.” Even years after our birth, we still remember those amazing moments, seeking more, savoring each new gift, while some of us still struggle with constant fear and worry that never goes away.

So with these parallels I smile, knowing that I, too, have given birth. I have experienced some of the parallel emotions of pregnancy even without ever conceiving. This is in essence my own virgin birth, given as a gift from God so that I can be aware, experience a miracle and truly appreciate each moment. Maybe this makes me a better genetic counselor: I don’t know.

Ana is 37 and has CF. She lives in Redwood City, CA.

INTERNET continued from page 29


Allergic bronchopulmonary aspergillosis (ABPA) is an important complication of cystic fibrosis. It is a hypersensitivity reaction to Aspergillus fumigatus, leading to a Th2 CD4 response mediated by the release of specific IgE. If ABPA is not treated early, it can cause severe impairment in lung function and long-term lung damage. Hence, early recognition with a prompt diagnosis is important. Due to clinical and radiological features of ABPA overlapping with those of bacterial or viral pulmonary exacerbations in cystic fibrosis, diagnosis can sometimes be difficult. Specific criteria for making the diagnosis of ABPA have been suggested. Newer serological tests, such as specific IgE to recombinant allergens and the detection of thymus- and activation-regulated chemokine, are being developed to improve early detection and monitoring of ABPA with greater sensitivity and specificity.

http://tinyurl.com/blu2g4

FYI


The treatment of cystic fibrosis has improved significantly over the past three decades. Median survival has improved by decades and is now estimated to be 37 years. Many factors contribute to improvements in disease severity and outcome. This paper reviews the current evidence of three groups of important factors: genetic, environmental and health-care related.

http://tinyurl.com/cz43w7


There are increasing reports of bowel cancer in cystic fibrosis, suggesting a possible causal link. Individuals with cystic fibrosis who have advanced lung disease present a high operative risk, limiting curative treatment options in early bowel malignancy. We discuss the complexity of the management decisions for cystic fibrosis patients with severe lung disease and early stage colonic malignancy, particularly in the context of potential need for lung transplantation. The case demonstrates that cystic fibrosis patients with very severe lung function impairment may undergo laparoscopic abdominal surgical interventions without compromising postoperative airway clearance.

http://www.jmedicalcasereports.com/content/2/1/384


Gastroparesis occurs in patients with cystic fibrosis, even in patients with relatively preserved lung function and in those without cystic fibrosis related diabetes. Macrolides may be an effective therapy in cystic fibrosis patients with gastroparesis when administered acutely or chronically.

http://tinyurl.com/bp8vta

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Welcome back to another edition of Unplugged. I must begin with an apology for missing the last issue. While I was having some CF-related health issues (I was on IVs at the time), I was also wrestling with computer issues. But I am back; and to be quite honest, things are better than ever. This year I am working on “going from good to great,” a concept a teacher of mine introduced in a class I’m taking. I want to make sure that CF is not what I’m all about and want to continue to experience all that’s out there.

On that note, I’d like to introduce our latest interviewee: Maggie Sheehan. If you do not know her, I think you should. She is young, motivated and fun. I have known her for a few years now and am impressed with her dedication to working on CF-related projects. In addition to having a seemingly unbreakable spirit, she is currently keeping very busy and is on track to graduate from college. She is on the Board of USACFA, she set up a foundation to raise money for CF—called Maggie’s Miracle Makers—and is involved with CFRI. She is one busy girl, and here’s her story:

1) Name: Maggie Sheehan
2) Age: By the time this article comes out I will be 21.
3) Where do you live? In the city of Chicago, Illinois, on the campus of DePaul University.
4) When were you diagnosed with CF? At 13 months of age.
5) Who is your doctor? Hospital? Do you like him/her? My doctor is Susanna McColley, and I go to Children’s Memorial Hospital. Yes, I love Dr. McColley. She has been taking care of me since my first hospitalization at the age of six.
6) How would you describe your health now? I frequent the hospital about every two months. I still lead a pretty normal life, but I work hard with treatments and nutritional supplements to have a part-time job and go to college full time.
7) What is the newest music in your iPod/CD player? I listen to the radio most days—to most of the top hits.
8) What is your favorite music in your iPod/CD player? My favorite music right now is Missy Higgins; she just came onto the scene.
9) Are you working? How are you doing with that? I do work part time at the Children’s Memorial Hospital Foundation. I work 1½ days-a-week. It works out perfectly and keeps me from sitting on the couch, watching TV. I also go to DePaul University full-time and am pursuing a degree in Public Relations. School can be very hard on me, especially this year. I can feel my health declining. I am just hoping to graduate next year without having to think about transplant.
10) Do you believe in a Higher Power? Are you religious? I believe in something bigger than me, but organized religion was never a big part of my life. I think we all have a certain destiny that is given to us at birth, and I also believe everything happens for a reason.
11) What are your hobbies? Does CF interfere? I just started a great hobby. I have been taking improv classes at a big improv theatre in Chicago. I have met great people and it keeps me active one night each week. It does make me cough a lot because I laugh in class all the time, and sometimes I feel my cough is disruptive. No one knows I have CF in the class just because it has never come up, and I actually like being known as just the girl who goes to college. That rarely happens in my life—when no one knows I have CF.
12) What is your relationship status? Happy about that? Does CF interfere? My relationship status is single. Some days it is great, some days it is not. I feel that most guys I come in contact with in college could not handle a lot of the things I go through on a daily basis, just by experience. But at this point I am happy with where I am and, hopefully, I will find someone who can handle CF and all of its struggles.
13) What is your most embarrassing CF moment? I think any public bathroom situation can be embarrassing.
14) What gets you through the tough days? On tough days I allow myself a certain amount of time to sulk/be aware of the sadness or frustration I am feeling. I then quickly find something positive out of the situation, or I tell myself I need to surrender to the process, which helps me not to...
worry and realize certain situations are out of my control.

15) What do you hate most about CF? Saying “No” to friends on a Friday night, or having to cancel plans at the last minute. I have two, actually. I also hate lung bleeds!!!!!!!

16) What is your favorite movie? TV show? Why? My favorite movie of all time is “My Best Friend’s Wedding.” It was filmed in Chicago and the lead actress is Julia Roberts, whom I have always loved. I saw it when I was young and I always imagined myself getting married in some big beautiful hotel just like in the movie (I think I need to marry a wealthy person for that to happen). My favorite TV show is LOST. Such a complicated show, but I appreciate it for how smart the writers are and how clever the story line can be.

17) Do you have kids? Want them? I do not have kids, but I have always kept my mind open to having one. I know my body is not healthy enough to carry my own child, but I would like to either adopt, try surrogacy or, maybe, foster young children. This is all tentative depending on my health in the future.

18) What do you look forward to? I look forward to finding a job after graduation and making as big a difference in the CF community as I can by sharing my own story with others.

19) Do you think having CF is a good thing or a bad thing? I think it is a good thing. Because of CF I am a very grounded person and it has given me some of the best friendships I could ever ask for. It has made me learn about life very quickly and most of my friends or loved ones come to me for advice because of my insight on life.

20) Tell us about your friends. My friends are very supportive people. Going to college was a great thing for me because I found great people to surround myself with. They are typical college kids who like to go out and have a fun time but also understand the limitations I sometimes have, and will accommodate me when they can.

21) What is your favorite color? My favorite color is blue.

22) Do you spend time with other people who have CF? If so, what do you do, and how important is this to you? I do spend time with others who have CF. I have found myself reconnecting with people from when I was younger, when we stayed in the hospital together. My one CF friend is hard of hearing and we both know sign language, so we like to get together with others who know sign language and sign to each other. I also spend time with other CF adults every August at a CF retreat in Menlo Park, California. I met some great people at retreat and it is so fun to hang out with my “people” for a week and talk and play games and eat - A LOT! It is so important to me to have a CF community that I can be a part of. I really felt lost in high school because of lost connections with people who have CF. It really keeps me sane knowing I have people to reach out to, who understand what I am going through in a time of need.

23) Do you spend time educating yourself about CF? How important is this to you? What effect does this have on your treatments? Rapport with your doctors? Self-Image? I do keep myself updated on what is going on with new treatments and new discoveries with CF. I have gone to the CFRI conference for the last three years, which always gives me a wealth of information. I also get information from the medical staff I work with at the hospital or new medical staff that I meet; like a patient who knows their own disease and, therefore, knows their own body very well. My doctor keeps me updated on information, as well, and that helps with our relationship. Instead of her always telling me what to do, we can collaborate on what is best for my health care regimen. I feel good about knowing the latest things with CF, and I am always glad I can share it or discuss it further with my CF peers.

That’s Maggie. I appreciate the way she balances her life with the realities of CF. She is not in denial about her health but also does not let it stop her. How many times do we get caught in the self-pity trap? The “I do not want to do my treatments” thought pattern? The thought that life is unfair? Why can’t I have the boyfriend/girlfriend? Or why do I have no money? Or whatever it is that makes you mad about having CF. All legitimate issues. But the question is, does it stop you, or does it motivate you to get creative and get beyond it? Personally, I do get caught up in those emotions, sometimes, but not as often as I used to. Today, I’m doing better at putting things in perspective. But I cannot deny them, because if I deny them they control me. Through a combination of a good attitude, perspective, CF support and friends, Maggie seems to have found a good balance on how she deals with life.

CF is a complicated disease both physically and emotionally, and we all need help and support to get through it. While we all are different and find various ways to make our lives work, the important thing is we don’t have to tackle all of these issues and challenges on our own. Maggie is a good example of how that is true. In addition, she has a great mom who is a lot of fun to hang out with, is very perceptive, and no doubt is a big support.

If you want to be interviewed for Unplugged, e-mail me at: rdenagel@usacfa.org. If you have tried previously, please try again - as I lost all my old e-mails when my computer crashed.

Rich is 40. He has CF and is a Director of USACFA. His contact information is on page 2.
CYSTIC FIBROSIS RESEARCH, INC.

PRESENTS

The Power of New Possibilities:
Growing Stronger and Living Longer with CF

22nd National Cystic Fibrosis Family Education Conference
Sofitel San Francisco Bay, Redwood City, CA
July 31 - August 2, 2009

TOPICS AND SPEAKERS INCLUDE:

“A Swedish Care Model: What We Can Learn”
Birgitta Strandvik, MD, PhD, Göteborg University, Göteborg, Sweden

“Clinical Research Update: Keeping Up with New CF Treatments”
Mark Dovey, MD, St. Christopher Hospital Philadelphia, PA

“New Findings to Address Tough Psychosocial Challenges in CF”
Alexandra Quittner, PhD, University of Miami, FL

“Sex Hormones: How They Play A Role in CF Health”
Marcia Katz, MD, Baylor College of Medicine, Houston, TX

“Drug Therapy in CF: Treating Today’s Problems while Investing in the Future”
Robert Kuhn, PharmD, University of Kentucky College of Pharmacy, Lexington, KY

“A Sister’s Story: My Path to Becoming a CF Nurse”
Ronni Wetmore, RN, Adult Cystic Fibrosis Center, Jacksonville, FL

REGISTRATION:

Early Bird Registration on or before 7/1/09: $150 per person
Regular Registration after 7/1/09: $175 per person
All meals included
Precautions to avoid cross-infection are rigorously followed by CFRI and hotel staff
Scholarships are available for eligible applicants
Significant hotel room discounts via CFRI’s web site: www.cfri.org
For more information, contact CFRI at (650) 404-9975 or cfri@cfri.org

CYSTIC FIBROSIS TEEN & ADULT DAY RETREAT

THIS YEAR’S THEME:

The Great Outdoors: A Breath of Fresh Air
Meet Some Great Friends! • Feel Like You’re Not Alone!
Learn more about taking care of your CF! • This is a place for hope and healing!
August 2–August 9, 2009
Located at Vallombrosa Center in Menlo Park, California

Who Can Come: Teens and adults 15 years and older with cystic fibrosis, their family members, friends and health care providers
Purpose of the Day Retreat: The retreat provides a safe and welcoming environment aimed at enhancing positive coping skills, social support and education for people who share common experiences with CF.
What We Do: Activities that promote health include daily exercise, arts and crafts, rap sessions, and educational workshops with guest speakers. Fun group-bonding activities include a talent show, games, and just hanging out getting to know others.
Cost: $65 per person for the entire week. Daily fees are $15 per day for visitors or $10 per meal for those who drop in for a meal only. Overnight accommodations and transportation are the responsibility of participants. Scholarships are available for those unable to pay fees.
Safety: All people with CF are required to comply with cross infection behavioral precautions. A medical advisor is available at all times, and volunteers are available to assist with respiratory treatments. Participants with CF must obtain a sputum culture before the start of the retreat.
People who have ever cultured Burkholderia cepacia, cultured Methicillin-resistant Staphylococcus aureus (MRSA) within the past 2 years, or are currently resistant to all antibiotics will not be allowed to attend the retreat.
We’d Love To See You There!
For An Application, Please Contact:
Cystic Fibrosis Research, Inc.
2672 Bayshore Parkway, Suite 520, Mountain View, CA 94043
Phone: (650) 404-9975/ cfri@cfri.org/ Fax: (650) 404-9981/ www.cfri.org

Article in Press Respiratory pathogens from CF patients can contaminate their hands and the clinic environment, but the actual risk of patient-to-patient transmission in the outpatient setting remains difficult to quantify. These findings support several CF infection control recommendations including hand hygiene for staff and patients, contact precautions for certain pathogens, and disinfecting equipment and surfaces touched by patients and staff.

http://tinyurl.com/c89wto

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

For a directory of pharmaceutical companies that provide free prescription drugs to patients who qualify, write to: Directory Programs, Pharmaceutical Manufacturers Association, 1100 15th St. NW, Washington, DC 20005-1707. Use the information provided in that directory to contact the appropriate companies for information on their specific programs.

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.


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.