CF Roundtable
A NEWSLETTER FOR ADULTS WHO HAVE CYSTIC FIBROSIS SPRING 2012

It's Not Fitness; It's Life

By Julie Desch, MD

I am well on my way to a 52nd birthday as a double delta f508, and I still have reasonably good function – breathing with the lungs I was born with. It feels strange to write such a sentence. To this day, I don't understand why this is true, when it wasn't true for my genetically similar older siblings, or for many of my dear friends with CF. What a weird disease. The only thing I know that I do now and have always done differently than my older CF siblings is exercise. Maybe this is it…maybe this is the secret. I don't really know, but since it is my only real clue, I feel obligated to write and talk about its importance at any opportunity.

For thirty-eight of my 51+ years, I have been compelled to exercise. Being a rather curious soul, I have tried many different types of workouts, always searching for the one best thing. As you might imagine, I've learned a few things. For one thing, the one perfect workout is the one you will do, and if that means that, like me, you get interested in a new thing every two months, so be it. But let me put on my sage "old survivor" hat for this article and tell you what I know to be true about exercise from my n=1 experiment of 38 years.

JULIE DESCH, MD

I have been both optimistic and pessimistic about my ability to exercise, and I assure you that optimism is by far the better course of action. Of course, it is very easy to take the attitude of the pessimist. One common thought process goes like this:

Why work out? It is hard and unpleasant and, as soon as I make any progress after hours and hours of work, I will inevitably get sick, end up in the hospital, and lose all the gains that I've made. What's the point?

Talk about being pessimistic! Although shades of this are slightly true (you likely still will get sick, occasionally), this one is pretty easy to dispel. This negative way of thinking about exercise doesn't hold water if you extrapolate it to other areas of life. Imagine saying, "Why raise a family? The kids are just going to move away some day and break my

Continued on page 26

INSIDE THIS ISSUE

Mailbox 3
Looking Ahead 3
Ask The Attorney. 4
Spirit Medicine 6
Speeding Past 50 8
Focus Topic 10-16, 24
Power of Two Movie Available Nationwide. 11
Sustaining Partners. 13
Through The Looking Glass. 17
Photo Pages 18-19
CFRI Conference and Teen & Adult Retreat 20
Milestones 21
Information from the Internet 21
Benefactors 23
Club CF. 27
Coughing With A Smile 28
In the Spotlight 30
Conversation Corner 32
Airline Travel Information 33
Subscribe Online Info 34
Subscription Form 35
CF Living. 35

CF ROUNDTABLE
FOUNDED 1990
Vol. XXII, No. 2

CF Roundtable (ISSN 1057-4220) is published quarterly by the **United States Adult Cystic Fibrosis Association, Inc.** (USACFA), a totally independent, 501(c)(3) tax exempt, nonprofit corporation whose Board of Directors all have CF. Articles in *CF Roundtable* may be reprinted only with advance written permission from USACFA. All submissions to *CF Roundtable* become the property of USACFA and should include the author's full name, address and phone number. Submissions are subject to editing as needed and we reserve the right to edit any comments that disparage another person either by name or situation. Requests for anonymity will be honored.

USACFA needs your tax-deductible donations to fund the printing, production and mailing costs of *CF Roundtable*. A yearly donation of $15 for individuals, $25 for non-U.S. addresses (U.S. funds only) and $25 for institutions is requested. However, CF Roundtable always is free of charge to those who are unable to donate. A fully completed subscription form is required to add your name to our mailing list. (If you have CF, please include your birth date.)

CF Roundtable does not give medical advice. Any medical opinions represented in these articles are those of the writer and do not represent the views of USACFA. We strongly suggest you consult your doctor regarding any medical references and before altering your medical regimen in any way. USACFA does not endorse any products or procedures.

United States Adult Cystic Fibrosis Assn., Inc.
PO Box 1618
Gresham, OR 97030-0519
Voice mail: 248-349-4553
E-mail: cfroundtable@usacfa.org
www.cfroundtable.com

EDITOR'S NOTES

Spring is here, at last. All of the country has experienced weird weather phenomena this year. Also there has been a particularly nasty respiratory virus making the rounds. It hung on for eight weeks for me. I hope it missed you and, if it didn't, I hope that you are feeling much better. Now I am enjoying daffodils and primroses and birds building nests. Hooray!

I hope you already have read **Julie Desch's** column, "Wellness", which starts on page 1. She discusses exercise and how important it is to us and our health.

Beth Sufian answers some questions about Social Security SSI and SSDI benefits in "Ask The Attorney".

Our Focus topic this time is: "Are You An Optimist or A Pessimist?" This was an easy topic for me and I enjoyed writing about having been born happy, in "Speeding Past 50". **Radie Stroud** writes of having been a pessimist and now being an optimist. **Debra Radler** says that she is "by nature" an optimist. **Jim Chlebda** makes an encore appearance with his thoughts on optimism and **Nicole Matthews** chimes in with her views on being optimistic. Then comes **Mark Levine** who says that "negativity is not in [his] vocabulary." **Jennifer Hale** rounds out the discussion in "Coughing With A Smile", where she talks of being happy that there is any liquid in the glass.

Be sure to look at "Information From The Internet", which **Laura Tillman** compiles for us in each issue. She does such a fine job of searching out interesting info and presents it in an easy to use format.

Jeanie Hanley and **Andrea Eisenman** have interviewed **Evan Burton** for "In The Spotlight". Evan is a musician who had a bilateral lung transplant last year and is ever optimistic. Be sure to contact Jeanie and Andrea if you would like to be interviewed for this feature of the newsletter.

In the "Conversation Corner" you will find **Maria Fioccola** telling us of a book of poetry that she has written.

There are a couple of special spots to mention. Check out page 11 for an announcement regarding "The Power of Two" and where it will be shown. On page 20 you can read about the upcoming educational conference and retreat that are sponsored by CFRI.

Information on air travel is available on page 33. The numbers and e-mail address for rules and assistance are listed there.

Be sure to check out our photo pages and "Through the Looking Glass" to see what CF looks like.

As I write this, I am nearing my 68th birthday anniversary. It is wonderful to be able to complete another trip around the sun. I figured out that, with making a complete rotation of the earth each day and making an orbit of the sun each year, I have traveled about 39,726,812,560 miles. Not bad for an earth-bound being! Wahoo! Let's all keep on racking up those miles.

Stay healthy and happy,

Publication of CF Roundtable is made possible by donations from our readers and grants from Sustaining Partners - CF Services, a bequest from the estate of Pamela P. Post in honor of Kathy Russell, Abbott and Boomer Esiason Foundation.

Mailbox

[A donation is made] in gratitude for a wonderfully fun and interesting newsletter. Though I personally do not have CF, I consider myself "sister" to Kathy Russell whose husband, Paul, is my first cousin.

Laurie Worth
New London Township, PA

Great job! Love *CF Roundtable!* Thanks!

Anabel Stenzel
Redwood City, CA

I can't wait to receive the next quarterly issues [of *CF Roundtable*] and look forward to the next topics. The Pet Therapy stories had us all crying and laughing.

Reading Ms. Sufian's article about career choices and frank discussion was insightful into the patient/ physician relationship.

Our center is involved in lung transplantation and end of life issues on a daily basis.

Keep up the good work!

Kind regards,
Bethanne Wenger, RCP. B.A.
Respiratory Technician
Adult Cystic Fibrosis Center
Baylor College of Medicine
Houston, TX

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) 2012: Are You An Optimist Or A Pessimist?

Summer (August) 2012: Respiratory Therapy Activities. (Submissions due June 15, 2012.) How do you pass the time during your treatments? Do you multitask during your treatments? We want to know what activities you've tried, what has worked for you, what doesn't work.

Autumn (November) 2012: Organ Transplant - Has It Met My Expectations? (Submissions due September 15, 2012.) Tell us about your life since transplant. What was your quality of life before and after? How has your life changed? Would you consider doing it again? Are there things you would do differently, if you had it to do over?

Winter (February) 2013: Osteoporosis, Osteopenia And Other Skeletal Issues. (Submissions due December 15, 2012.)

ASK THE ATTORNEY

Answers Regarding Social Security (SSI and SSDI)

By Beth Sufian, JD

The Social Security Administration (SSA) wants to make sure those citizens receiving Social Security Disability Insurance (SSDI) benefits or Social Security Insurance (SSI) benefits meet both the medical and non-medical SSA eligibility rules. In fact, in recent hearings before Congress, Congress made it clear they wanted SSA to make sure that those receiving SSDI and SSI met all eligibility requirements. In the past some people with CF could receive SSA benefits for many years and never have their cases reviewed by the SSA. The lack of timely review for CF benefit recipient's files is changing.

Many people with CF are now receiving notices in the mail indicating that their SSA file is being reviewed. SSA is requiring individuals to submit medical evidence as well as evidence related to the SSI income requirements and SSDI work requirements. These forms are very important, and they must be completed and submitted to SSA within a certain number of days. A person with CF who fails to submit the SSA review paperwork can have his SSA benefits terminated, even if he meets the SSA medical and income criteria. Individuals with CF should take the completion of these forms very seriously.

Individuals can contact the CF Social Security Project and possibly receive free help with their SSI review. The CF Social Security Project is a case management project funded by the CF Patient Assistance Foundation which is a subsidiary of the CF Foundation. The CF Social Security Project can assist people with CF, who meet both income and work requirements, with their SSI or SSDI applications and also can assist with some SSA review cases. The CF Social Security project can be reached at 1-800-622-0385.

Nothing in this column is meant to be legal advice about your specific situation. If you have questions, please contact the CF Legal Information Hotline at 1-800-622-0385 or by e-mail at: CFlegal@cff.org. The Hotline provides free and confidential legal information to people with CF, their families and their CF Center care teams, and is proudly sponsored through a grant from the CF Foundation.

Question 1. How does SSA determine if I am eligible for SSI benefits under their income rules?

In addition to determining if someone meets the SSA medical criteria, SSA also must determine the value of an individual's resources on the first day of the month for which benefits are requested, when a person is applying for SSI benefits. Resources that SSA counts include: cash, money in bank accounts, stocks, savings bonds, land, vehicles, trusts and 401(k) retirement accounts. An individual may not have more than $2,000 in "countable resources". A couple or family may have no more than $3,000 in countable resources. Transferring ownership of a resource or asset can affect the value of an individual's countable resources, which in turn affects SSI eligibility. Sometimes potential SSI recipients must sell or transfer an asset in order to decrease their countable resources below the SSI threshold. However, it is important to understand that the way in which you transfer or dispose of a resource can also affect your SSI eligibility.

As of 1999, transferring ownership of a resource for less than fair market value results in a period of ineligibility for SSI. The rules governing the duration of a period of ineligibility are complicated, but an invalid transfer can result in ineligibility for up to 36 months. Therefore, when an individual reports to SSA that a resource has been transferred and is

> *"A person with CF who fails to submit the SSA review paperwork can have his SSA benefits terminated, even if he meets the SSA medical and income criteria."*

BETH SUFIAN

no longer in his or her possession, the SSA must determine how the transfer occurred and for what value in order to determine if the transfer of the resource was valid.

The Social Security Administration defines an "invalid transfer" as either giving away or selling a resource for less than fair market value. Significantly, the SSA explains in their rules that simply giving away cash to another person is an invalid transfer of resources. This means that a person who transfers money to a friend or relative will have that amount of money count as a resource for up to 36 months making that person ineligible for SSI benefits due to the asset. Although many people who are applying for SSI benefits are tempted to give away excess cash in order to stay below the SSI resource limit, this is an invalid transfer which will result in a transfer penalty and should be avoided.

One way to dispose of excess cash is to either purchase a good for fair market value or pay down existing debt. Payment of existing debt is considered a valid transfer as long as the debt is in the name of the beneficiary. For example, if a person owes $4,000 on a car loan and has $4,000 in cash in the bank, the person could use the money to pay off the car loan and this would be a valid transfer of the money. In the case of a minor child who receives SSI, a parent may use his assets to pay down existing debt in his name as well.

Valid transfers also exist. Valid transfers allow an individual to maintain or attain SSI eligibility and are permissible in certain situations, including selling property for fair market value, exchanging property, spending cash (you must purchase goods for fair market value) and transferring the name in which a financial instrument is held (e.g., stocks or bonds).

The Social Security Administration does not care what assets are sold or disposed of as long as they are sold for current market value. For example, if a person owns a boat which is valued at $4,000, the potential SSI recipient cannot sell the boat for $1,000 to stay below the asset rules. In other words, a beneficiary cannot deliberately undervalue or overvalue goods and services merely to achieve SSA eligibility.

This is not an exhaustive list of ways to transfer assets in a way that will be considered valid by the SSA. For more information on transfer of asset rules, please call the Cystic Fibrosis Legal Information Hotline at 1-800-622-0385.

Question 2. What date does Social Security consider my date of disability?

The SSA date of disability should be a person's last day of work. However, when determining what date Social Security Disability benefits start, a person must count the first five full months from the date of disability. For example, if a person stops work on February 20, 2012, the first full countable month is March 2012, the five-month waiting period will end in July 2012, and the first benefit check will start August 2012. This is *very important* for people to understand.

Many people with CF do not realize that there is a five-month waiting period before SSDI benefit checks begin. This means that a person with CF must have five months of savings to cover living expenses during this period of time. The only way a person will receive benefits during the five-month waiting period is if that person has less than $2,000 in assets and, therefore, will be eligible for SSI benefits in the first full five months that person is unable to work. The person will also receive Medicaid during those months because she is eligible for SSI benefits. However in the sixth month of being unable to work, the person will become eligible for SSDI. If the SSDI check is larger than the SSI amount, the person will lose SSI and lose Medicaid.

Likewise, Medicare eligibility is also determined by counting months from the date of disability. Medicare benefits start 29 months after the first full month a person became unable to work. If a person stops work on February 20, 2012, the first countable month is March 2012, and Medicare benefits will begin 29 months later in August of 2014. As I have written in previous columns, a person must make sure he uses COBRA to extend private health insurance benefits that had been provided by his employer so that he has coverage during the 29-month Medicare waiting period.

There are certain rules a person must follow in order to get the full 29-month extension of COBRA so that he has insurance coverage until he becomes eligible for Medicare. In my next column I will review those rules. If you need the rules sooner please contact the CF Legal Information Hotline. If your employer does not offer health insurance, then you will need to look into other options for coverage during the 29-month waiting period for Medicare. If you are not eligible for SSDI benefits and are eligible for SSI benefits, then you will not have to worry about a waiting period for Medicare to begin. Medicaid benefits will begin when SSI benefits begin. ▲

Beth is 46 and has CF. She is an attorney who specializes in disability law. Beth is a Director of USACFA. Her contact information is on page 2. You may contact her with your legal questions about CF-related issues.

SPIRIT MEDICINE

On Being Different: God Doesn't Make Mistakes

By Isabel Stenzel Byrnes

When I give motivational talks to CF families, the most common question that comes up is, "How did you deal with being different from your peers?" Being different is a *big* deal, not just for teenagers, but for people of all ages. In this *Spirit Medicine*, I will explore how we can make sense of being different on a spiritual level.

I am writing this article in an airplane. I travel a lot, and whenever I fly, I wear a mask to protect myself from germs. I walk up and down airports with eyes staring at me, necks turning and kids pointing. People reluctantly sit next to me in the plane, leaning away. I'm used to this, so to me it's comical to observe how freaked out people are by someone wearing a mask. It's worse than when I used oxygen, because people understood I had lung disease. With the mask, it's a guessing game.

Wearing a mask is just a petty physical reminder of my difference, but it represents a lifetime of feeling socially and emotionally different from my peers because of my cystic fibrosis (CF). When I look back to my younger days of extreme self-consciousness, it's amazing that a chronic illness could create such a perceived division between me and people around me. I tried to remind myself, "It's just a lung disease!" I knew everyone is different; I knew there are people with more challenging physical limitations than I faced, and that everyone fights her own battles. Cognitively, I understood. Yet, emotionally, I really wished I was normal. Even today, I sometimes find myself wishing the same thing.

After 40 years, I'm finally reconciling my disdain of being different with an understanding that my life might reflect a spiritual design. I often like to interpret my being born different as some sort of divine lesson. Let's go back to my longtime yearning to be normal. I don't think I'm the only one with CF who wishes this.

> *"I often like to interpret my being born different as some sort of divine lesson."*

ISA STENZEL BYRNES

It means a lot to me that I am married and have an education – because I have followed the normal path. I am so grateful. Yet, I yearn to have a successful career; I yearn to have children – because those things are the rest of the normal path. Everyone seems to have kids or a career. Following the routine of the normal people out there might bring me more happiness, but it might not. I have to ask, "Isn't the normal life just a little boring?" Perhaps it's overrated! CF invites us to 'subvert the dominant paradigm', or in plain English, to challenge social norms.

Now, I look back at my very dramatic life with CF: starting with a Make-A-Wish trip, to hospital visits of movie stars, to CF camp, to many intensified relationships with my CF and medical friends, to a memoir about living with CF, and now a documentary film about CF. Throughout all of these opportunities, I've met people from all backgrounds just because of the disease we share. What a blessed life I've had - all because of my difference! I realize not everyone with CF has had these positive experiences, but I bet if you really explored your life, you'd also find that some doors have been opened unexpectedly because of CF. Granted, this life story also has many climaxes, antagonists, and conflicts in its plot. Like some of you, I've had breathlessness and pain, I've almost died several times, and I've lost countless friends-- so there have been plenty of painful losses attributed to this

experience. Indeed, when we have CF, it seems that our lows are lower, because of the multitude of losses, but maybe we are challenged to see that our highs are also higher.

> *"I'm proud that I've lived as normally as possible given my CF, and that I made the most of the "difference" I've been given."*

When I yearn to be normal, I try to shift my perspective and see that my celebrations are even more celebratory. For example, my twin, Ana, and I climbed to the top of Angel's Landing at Zion National Park last fall. It was a harrowing last half-mile, straight up a narrow ridge with drops of 1000+ feet on each side. At the summit, Ana was ecstatic. She cried, "I think I'm the only double-double lung transplant patient on chemotherapy who has done this!!" I was thrilled for her, and for my own accomplishment. Whatever she is or I am able to do today is so much more meaningful because of the obstacles we've conquered in our past.

But learning to appreciate life more is a pretty simple lesson. Did someone decide that I had to work my butt off to earn my breath, just to teach me that?! What's that about? Some sort of cruel joke?

Okay, there have to be other benefits. Being different also forced me to look within, and explore deeper parts of who I am. I value my different perspective on life; I'm proud to be unique; I'm proud that I've lived as normally as possible given my CF, and that I made the most of the "difference" I've been given. I am grateful to my healthy friends who tell me they have learned about life, meaning, love and purpose just by knowing me. Those were the same junior high school friends from whom I was mortified to be different! Also, I have gained awareness that we live in a progressive culture that slowly but surely embraces different identities: people can assert their authentic selves and be proud of being disabled, gay, Latino, African-American, HIV+, or a survivor of abuse. Our society is starting to welcome difference, recognizing that we can learn from difference and be better people. Shame is out. I do not need to be ashamed of CF.

Yet, realistically, being different means putting up with social judgment, or fears of social judgment. It means building enough ego strength to tolerate teasing or downright mean people. I've also learned that I'm responsible for my self-consciousness, more than anyone else. I have a habit of putting my own thoughts into other people's heads: "The person I'm interviewing with probably thinks I'm flakey because of my illness," or "That person's staring at my chest, wondering what my mediport is." Actually, do I know what other people are thinking? Can I read minds? No! So, I don't have a right to impose my fears and anxieties on other people's thoughts. If I truly have an inkling people are wondering about something, I'll just have to ask. For example: "I wonder if you are worried that I'm infectious because I'm wearing a mask. If you are, I want to reassure you that I'm just protecting myself from infection." And, just letting go, and letting people think what they think, has helped me worry a lot less about other people's judgments.

In addition, I feel that God, or the Universe, has given me the personal resources to be strong enough to make sense of my CF. I was at a career event at Stanford one day, feeling very small as high-powered women shared their stories of climbing the corporate ladder and becoming CEO's of companies. I felt like I didn't belong and I was an alien surrounded by 'normals'. Suddenly, I received a divine message. Three words came to me: *God chose me*. For whatever reason, I was chosen to carry this burden of CF, to be able to live a different life and embrace it. I had to believe that not everyone was capable of doing so, but I could. For some reason, I was chosen to show normal people that it's okay to take a different path, to adapt to the uncontrollable, to live with limitations and still be tremendously happy.

Most importantly, I now believe my difference was planned. I recently saw a moving documentary film about a young man, Kyle Maynard, who was born without arms and legs, and became a champion wrestler. When he was five years old, he asked his grandmother, "Grammy, why am I so different?" And his grandma gave a long, loving explanation, and ended it with, "Honey, God doesn't make mistakes."

What a perfect statement! *God doesn't make mistakes*. This simple message consoles my insecurities by telling me that I'm okay as is. When our bodies are born different, we are not flawed. And Tiffany Christensen, author with CF, also states, "I am not a mistake." She seemed to be born

Continued on page 13

SPEEDING PAST 50...

For Me, The Glass Always Is Partly Full

By Kathy Russell

Although I am an optimist, there have been times in my life where I was pessimistic - times where I felt that there was little chance that a particular thing might work out the way that I wanted - times that seemed to have no chance of a positive outcome. Happily, I am able to say that many times those things came out okay. The majority of my life has been positive.

I believe that pessimism can be harmful to one's health. Often, a negative attitude can lead to a negative outcome. If one expects to fail, chances are that it will be a self-fulfilling prophesy. My feeling is that a lot of our health status is dependent upon our mental status. If we are always feeling sorry for ourselves, we become pitiful individuals. On the other hand, if we present a positive face we are perceived as "more normal" individuals. I prefer to be perceived as "normal". (I am referring only to my general health status, not to my mental status!)

Several years ago my husband, Paul, and I were at brunch with friends who had learned of the "Six Word Memoirs". These are a way to condense one's life into six words. They asked what six words I would use to describe myself. After thinking about it for a short while, I came up with the following: "Born happy, always stayed that way." That sums up my life in a nutshell.

I have been told that I was a happy child. My memories of my childhood certainly would support that thought. I have very pleasant memories of those years. Sure, there are memories of illnesses, but I choose not to dwell on those. Instead, I dwell on the good memories.

We lived in the country and I had 13 acres on which to play. (I thought that was a huge amount of land on which to roam. Compared to many of our neighbors, we had very little land. Many of them were farmers. We weren't.) I had special play places in the old-growth Douglas fir trees that covered much of our land. I was the youngest kid in the neighborhood. (The neighborhood covered about ten miles along a road!) My sister, who was next closest to me in age, was five-and-a-half years my senior. I know it was a pain for her to have to have Kathy tagging along with her. So I played alone, a lot.

I learned to listen to the sounds of the woods and to see the little creatures that inhabited them. I had a regular "jungle gym" of vine maples. These wonderful, flexible, small branches made the most terrific trapezes and swings. I was so happy playing there.

I am sure that playing out in the fresh air played a major role in keeping me healthy. I also took ballet, modern dance, acrobatics and tumbling at the local community center. (I think that what we called acrobatics and tumbling would be called gymnastics now.) All of these classes were so good for getting into shape and staying in shape. They were great for lung clearance too.

> *"I choose to see the positive aspects of my life. I am alive. I am able to get around on my own (thanks to my portable oxygen concentrator)."*

School was difficult at times and I missed many days – the equivalent of two years out of the first seven! In high school, I missed the equivalent of another year. I never felt that I would be unable to keep up with my classmates. I knew that I had to work hard to keep up with all my courses, but I did it and I graduated with my class. This was a major accomplishment for me, since this was before laws that required schools to accommodate people with special needs. I think it was good for me to have to compete on an even basis. No quarter was asked nor taken and I measured up. I learned that this is the world in which I was living and that I would have to manage. And I did.

KATHY RUSSELL

A favorite quote of mine is: *The*

pessimist sees the difficulty in every opportunity. The optimist sees the opportunity in every difficulty. I choose to see the positive aspects of my life. I am alive. I am able to get around on my own (thanks to my portable oxygen concentrator). I have been married for 47 years to a wonderful man. I have traveled to many interesting places in this world. I still have much to do and many places to see.

In the future I am sure that I will be able to travel, albeit with more rest stops than I used to need. I will gain back some of the lung capacity that I have lost. I will continue to do interesting things and meet interesting people.

I don't want to give the impression that I am some kind of Pollyanna. I am not dangerously optimistic. I know the realities of having CF. I know that many people are not as fortunate as I have been. I am very grateful to have lived for so long. Most of my friends from my youth have died, even many who did not have CF. I am old enough to be considered "old" by a majority of our population. Who would have thought that could ever be possible? I did.

When I was diagnosed with CF, at the age of 12, I overheard the doctors telling my parents that I wouldn't live another six months. I suppose that hearing something such as this could really "mess up" some people. It didn't bother me. I just figured that those docs didn't know what they were talking about and decided that I would outlive them. I have!

When it comes to statistics, I don't pay a lot of attention. I always remember that if a person has one foot in a bucket of boiling water and the other foot in a block of ice, statistically speaking - that person is comfortable! I think you can see that I am not impressed by statistics. They are fine for people who thrive on them, but they have very little to do with real life. If I believed in statistics, I never would have lived long enough to be diagnosed. The median life expectancy for someone with CF was about four years of age, when I was 12. That could have scared me, but instead it made me think that the statistics weren't very reliable.

I believe that if I had been pessimistic by nature, I never would have been able to overcome some of the roadblocks that I encountered in my life. I might not have persevered with my schooling, when I fell so far behind because of illness. I might not have gone on to further training after high school. I might have given up when I would miss weeks of work because I had a cold. I might never have married because I might have thought that I was going to die young.

Being an optimist, I was sure that I would live a long time. When I was 12, I think that my goal was to be 41. I have exceeded that by more than a couple of decades! I knew that I would graduate from high school, go on to nursing school, get a job and support myself. Marriage wasn't a big part of my plan. I wasn't looking for a mate, when I met Paul. I guess I was just lucky that we met. I certainly consider myself lucky to be married to him. We have had 47 good years together. We have had a wonderful life together.

Each time that I have gotten ill, I have been fortunate enough to be able to overcome whatever was attacking me and to survive. At some time I may not be able to, but as long as I can I will live life to the fullest.

This newsletter is another thing about which I was very optimistic. When a group of us answered a plea for help from Lisa McDonough in 1990, I was sure that we could create an organization that would be able to represent adults who have CF. Also, I was sure that we could create a newsletter that would be informative and interesting. I believe that we have succeeded. *CF Roundtable* has been publishing for more than 21 years. My optimism was well-placed.

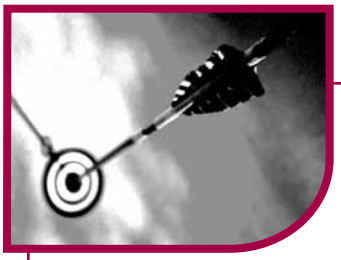
After 22 years of working on USACFA, I am happy to see that it is in good hands and I can retire from this volunteer job. I still will write this column and, as long as the Executive Editor will have me, I will continue as Managing Editor. I have decided not to run for re-election and will no longer serve as a Director of USACFA. I have enjoyed my years on the Board of Directors and I have enjoyed getting to know all of you. I am optimistic that we have many good years together still to come.

As long as there is one drop of something in my glass, I consider the glass to be partly full. (If there is anything in it, it can't be empty!) I still have CF, I still use supplemental O_2, I still am old, but I still am able to exercise and I still am happy to have my glass partly full.

I leave you with a parting thought:
The Lord gave us two ends to use:
One to think with, one to sit with:
Our lives depend on which we choose:
Heads we win, tails we lose. ▲

Stay healthy and happy,
Kathy

Kathy is 68 and has CF. She is a Director of USACFA and is the Managing Editor of CF Roundtable. Her contact information is on page 2.



FOCUS TOPIC

ARE YOU AN OPTIMIST OR A PESSIMIST?

A Recovering Pessimist

By Radie Stroud

Am I an optimist or a pessimist? I would like to say I'm an optimist. I often try to find the best in problems. For instance, I want to be alive to walk both of my daughters down the aisle and to give their hands away in marriage. Clearly, I understand that the odds of that happening are very low, but I believe I will be there.

Unfortunately, I haven't always been an optimist. As a child I was told that it was likely that I wouldn't live long enough to graduate from high school. Growing up as a teenager, while questioning your mortality, does something to you. At an age when most believe themselves to be immortal, I was trying to figure out why I was even going to school - since I clearly had no need for an education - since I wasn't going to live long enough to actually use it.

Today, I'm 34 years old. I have two beautiful little girls and a wonderful loving wife. Emma is my oldest; she just turned 3. Katelyn is a little over three months old. My wife and I both work full time. As you can imagine, our lives are very busy. We are always cleaning the house, only to see it get messed up three minutes later. Our mornings are filled with rushing to get dressed, getting the kids dressed, and getting everyone out the door to have our day. Oh yeah - let's not forget - I also have to find a way to work my breathing treatments into our hectic mornings. We are a typical suburban family with one important difference. I'm suffering from cystic fibrosis (CF).

As you can see, there is a stark difference between the first two paragraphs. As a child, I was very negative. As an adult, I try hard to remain as positive as I can. You might wonder what happened, what changed me so much? Well, without getting too sidetracked, I will say that something happened to me that I believe everyone with CF goes through at some point in his life. It's the turning point. Some get there very early in life. For others (like me) it takes a while to get there.

RADIE AND HEATHER STROUD.

One day I had to look at myself in the mirror and ask myself the tough questions… Do you really want a life? If the answer is yes, then what are you doing to earn your life? At some point every person with a terminal disease is faced with the challenge to either get busy dying, or get busy living. I was 26 years old when I had that realization. I was in the hospital and noticed my FEV_1 had dropped as much in one year as it had in the previous five years. I literally broke down into tears (those who know me, know that I never cry) which was a very emotional time for me. I quickly did the math and could see that I was about to be in serious trouble with my lungs, unless something changed - dramatically.

I recall crying like a baby in my mom's arms and telling her that I wasn't ready to die. I verbalized my desire to have a family and a normal life (something I never dared say before). I know my mother was in shock, but she didn't act like it. She just listened, held me tight, and told me it would be okay. That day in the hospital was a day that changed my life. I decided then and there that I wanted to live.

Subsequently, I began to read books that others with CF wrote, such as "Alive at 25" by Andy Lipman (my personal favorite). I got a gym membership and started working out regu-

larly. I got myself in a much better place both physically and mentally. Shortly after, I met the love of my life, Heather (exactly one year to the day after we met we got married). Funny how quickly things can change when you decide to make some changes.

Heather and I have been married for six years now. She is an incredibly special woman. She is the person who I never thought existed. She married me, knowing that I had a terminal disease, and that we would possibly never be able to have children. She didn't care, she loved me and she wanted to marry me. I can't say enough about her strength. She is a person who understands that I need to take treatments, and she picks up the slack when I get sick.

Since fatherhood, I've taken a new view of life. I've adopted a view that is spawned from genuine optimism. I'm optimistic that I will live to see my kids start elementary school, junior high, high school, college, and more. I'm actually planning for retirement with my wife (something I never thought would be a thing I would need to consider). As I'm saying these things, you might be thinking that I'm jumping the gun on my expectations, but I have to say I NEVER believed I would be where I am. I'm still here, so I have a new motto - "plan for the best and hope the worst doesn't happen."

> "I'm actually planning for retirement with my wife (something I never thought would be a thing I would need to consider)."

Truthfully, those of us who have CF have a duty to be optimistic. We all have close relatives and friends who love us very much. They look to us to find hope that only we can provide. If we are negative, we will hurt all those close to us. They need to know that we believe things are going to turn out for the best. ▲

Radie is 34 and has CF. He and his wife, Heather, live in Katy, TX with their two daughters, Emma and Katelyn. He is a Construction Manager for a developer. You may contact him at: radies@gmail.com.

Movie Available Nationwide

"The Power Of Two," the award-winning documentary featuring identical twins with cystic fibrosis, will be released on cable and satellite Video On Demand and digital broadband across the U.S. on June 5, 2012. The feature directorial debut of Academy Award nominee Marc Smolowitz, the film offers an intimate portrayal of the bond between half-Japanese identical twins, Anabel Stenzel and Isabel Stenzel Byrnes (author of our "Spirit Medicine" column), their lifelong battle with CF, survival through miraculous double lung transplants, and improbable emergence as authors, athletes and global advocates for organ donation and CF awareness. Since the film's world premier in L.A. and New York in July 2011, it has garnered ten awards and screened at over 25 film festivals and numerous community screenings in four countries.

For more information, go to www.ThePowerOfTwoMovie.com.

Clouds, Clouds Go Away, Point Me Toward A Sunny Day

By Debra Radler

I believe that optimism is a gift bestowed upon children at birth. Have you ever known a two-year-old pessimist? I've only known two-year-olds to reside in the land of sunshine and lollipops, yet I don't know many adults who still live there. Some of us might have a natural predisposition to see the sunnier side of things, while others will navigate toward the broodier side, but I think our general outlook on life is attributable to more than our disposition or temperament. I believe that the accumulation of *experiences* contributes greatly to the person we ultimately become. It would stand to reason that a lifetime of great experiences would contribute to a person's optimistic outlook and, conversely, negative experiences might make one a bit more pessimistic. Hopefully, the longer you live, the better chance you have of accumulating a balanced mix of experiences, and a more balanced or realistic look on life.

I think I am, by nature, optimistic. My childhood experiences were, for the most part, good. I tend to have a general sense of appreciation for the wondrous, awesome, inspirational gift in being given one more day - day after day. I also tend to reason, emote and interact in ways that engage and uplift, rather than deter and depress. I'm not certain if this is a choice I make, or a natural response, or even a learned response. I just know that eight out of ten times I will see potential or hope in almost any situation.

It isn't always easy to determine whether you are a pessimist or an optimist. It took me a fair amount of soul searching to come up with an honest assessment. After all, the outlook meter

DEBRA RADLER

is like a bathroom scale - the needle rarely stays fixed in one spot for all eternity. There will be times when the needle will hover over "P" so long that it makes the optimist crazy. And if the pessimist is lucky, there will be moments in life when that needle hovers over "O" long enough for him to feel the pure joy of optimism.

So what makes me believe that my needle swings more toward the "O" side of the scale? For starters, I buy toilet paper and paper towels in bulk. What die-hard pessimist would bother doing that? I have fallen in love enough times to know that love is a very optimistic endeavor. I've ventured into marriage twice. I believe my teenage step-children will one day become human again. I play the lottery. I do not eat dessert first. (But I always eat dessert!!) I pray to God. I get on elevators that are overly crowded—while praying to God! I hold season tickets to local theatre. I board an airplane with an expectation to get to my destination, despite a 20-year fear of flying.

About fifteen years ago I decided to acquire a hypoallergenic dog, fully aware that I have suffered from severe allergies to animals my entire life. It was a decision based purely on hope, optimism, and wishful thinking. And as I watched my eye blow up to the size of a golf ball, scratched the hives on my arms, and added additional nebs to my life for the asthmatic response, I never gave up hope that it was all a temporary reaction. As the symptoms began to subside and the love for this puppy began to grow, I did what any "sunshine and lollipop" thinker would do–I added a second pup to my life a few years later.

About ten years ago I stood at the base of El Castillo, a Mayan pyramid, in Chichen Itza, Mexico, looking up at people who were the size of paperclips, who had decided to climb the crumbling ruin with no guard rails. I thought about the 98-foot climb upward, the breathtaking views that awaited me, and more importantly, the impending, inevitable, perilous, steep descent; and I thought to myself, "That looks like fun!" My boyfriend abstained out of fear, but I was not deterred. My meter hovered all over "O" that day.

More recently, I clawed my way out of a miserable, four-month-long exacerbation of disease in order to become healthy enough to enjoy a trip to Paris! And, finally, when I look at pictures of me and my handsome husband, I envision us in photos years later with a few more wrinkles, gray hair, and a little more give to our belts.

The diagnosis of a life threatening disease and the challenges of learning to live with it are experiences in our lives that can definitely taint our optimism. It can catapult us from wearing rose colored glasses to night vision goggles in a heartbeat. I have struggled with the emotional and physical tolls that cystic fibrosis has contributed to my life, but I still think that I have enough of an upper hand to continue the relentless fight. Dwight D. Eisenhower once said, "Pessimism never won any battle." and I would have to agree with him. If you believe it to be insurmountable, you will find a way to self destruct. If you believe it to be at least manageable, and battle-worthy, you will fight it with the right mix of hope and realism.

When I was two years old, I'm certain that I was a "lollipop and sunshine" thinker. Now, I'm probably some sunshine, less lollipop. Even so, I don't deny myself moments of pessimism. I don't even deny myself long periods of pessimism. But I have known enough pessimistic people in my life to know that I would not be happy being one. I always find a way to eventually escape those doldrums and negative vibes, and convince myself that something better awaits me. I will turn 50 in May. It will be a good birthday. It was my "goal" birthday, set back in the day, when it was a pretty unrealistic goal. At nearly 50, I don't really dwell on my life expectancy anymore, since I've surpassed it. I think about what I will eat for dessert tonight, and where I will celebrate my milestone birthday. Beyond that, I will put on my rose colored glasses, get in my car and enjoy the ride! ▲

Debra is 49 and has CF. She is a semi-retired CPA living in Roselle, IL with her husband, Adrian, and two Bichon Frise dogs. She can be contacted at: debraradler@hotmail.com

STENZEL *continued from page 7*

with such a conviction. If only we were all so lucky to be given a message of our worth and perfection at such a young age.

I recently heard about a man with CF who ran a marathon with much struggle, and then proposed to his girlfriend at the finish line. Though I admire anyone who runs marathons, it seemed like he wanted to prove that he was strong enough to be a husband to his girlfriend. Was he not worthy of being loved by a wife, by being committed to, by being trusted as a reliable husband, for just being himself, without this arduous means test? Did he have to prove that he wasn't different from healthy men, despite having CF? In a way, I can relate; I remember me pushing myself in graduate school, just to keep up, or going to the bathroom at work, spitting up cups of blood, and then going back to the office – just to prove that I was just like everyone else. My drive to be productive, successful and normal nearly killed me. I wish someone had counseled me that I didn't need to prove anything. Today, I hope that all with CF are graced with the chance to ultimately see that they are loveable, worthy, meaningful human beings – no matter what.

If you are reading this *CF Roundtable*, I imagine it's because it helps you realize that you are not alone in your CF, or your loved one's CF. I also imagine there are times when your difference makes it hard for anyone to understand or relate to your experience… but people with CF can understand. Knowing other people with CF has given us a sense of belonging. We are different, but not too different. We are so blessed to have each other.

May you find spiritual consolation in your own acceptance of your difference. I pray that we all can see ourselves as unique and perfect creations, just the way we are. ▲

Isabel is 40 and has CF. She and her husband, Andrew, live in Redwood City, CA. You may contact her at: Isabel@usacfa.org.

Damn Lucky–the Misadventures of a Born Optimist

By Jim Chlebda

'ALL FIVE' IS THE PHOTO I MENTION IN THE ARTICLE THAT MY DEAR OLD MOM HAS ON HER WALL; ALTHOUGH SHE ADDED B&WS OF OUR YOUNGER BROTHER MARK, TO THE UPPER RIGHT CORNER AND OUR YOUNGEST SISTER CATHY [AS AN INFANT], TO THE LOWER LEFT. THE MAIN IMAGE IS L TO R, OLDER BROTHER BOB (6), SISTER KAREN (2), AND ME (SIX MONTHS).

I got my incorrigible head of curly hair from Grampa Ziggy. And, thanks to my parents, I was blessed from birth with unbridled optimism, an innate sense of intuition and a healthy dollop of skepticism. These inherited traits would hold me in good stead for the decades that followed. They are ideal attributes that enable me to grapple with something *else* that I inherited. I was born in the winter of 1957 in Chicago, Illinois. Four days after my birth, my apprehensive young parents got the one-two punch—their newborn son had something called *meconium ileus*, and immediate surgery was imperative. A sweat test confirmed the physician's suspicions that something called *cystic fibrosis* (CF) was the culprit. My folks were stunned. I was the third of five children they would have. My youngest sister, born in 1964, was diagnosed with CF a few years after her birth.

On some primordial subconscious level, through the trauma of that neonatal surgical ordeal and the two months of post-op recovery, I must've somehow rationalized that if I pulled through *that*, the worst was behind me. Everything that lay ahead was bound to be worth the price of admission *(well, maybe)*. And, in spite of that grisly start, an early diagnosis was another blessing of sorts. There would be no guessing months or even years down the road that something was amiss.

My folks, once over their shock, were supremely attentive to my (and later, also my sister's) specialized medical and nutritional needs. They also immersed themselves into a whole new world, diving headfirst into the fledging Cystic Fibrosis Research Foundation - Chicago Chapter, where my father served as director from 1959–'69 and treasurer from '59–'62; then again, as president of the South Unit C.F. Research Foundation in 1964 and treasurer in '69, hoping they could make a difference and help find a cure. Their unconditional love was unwavering.

Among the photographs dear old Mom still has on her bedroom wall is my older brother, Bob (6), sister, Karen (2), and me (at six months, I'm told). The expression on my face is a perfect metaphor for the optimism that I have carried with me each and every day—it draws wonder and a laugh every time I see it. Perhaps I've just been damn lucky—but damn grateful and appreciative each year as my life's long, winding road of adventures has unfolded.

Can't recall those earliest months in the hospital, but from early memories as a child, I learned soon enough I had this "thing" they called cystic fibrosis. Back then, every meal was preceded by Mom patiently shoveling the obligatory pile of ghastly, bitter enzyme granules into my mouth on a spoonful of grape jelly—***Yeeuckk!… why me?*** But, if that's what I needed to digest food, I guess I couldn't complain too much.

As I grew into a youngster, I walked, ran and rode bikes with childhood

friends all over our Southside, Chicago neighborhood. Unable to tie me down for 'postural drainage', my folks gave in early and let me run and play like there was no tomorrow—for which I am grateful to this day. And me, not thinking twice about the fact that kept them awake with worry at night those early years, as the survival age with CF was in the single digits. More important to me was my first insightful discovery—one that would stick. When I got hot and sweaty from playful exertion, my chest would heat up and thick mucus would literally melt out of my lungs, which I could then cough up easily. To my young mind, my "CF" problem was solved—just play hard, all day! I also gained an affinity for pretzels at a young age, my body craving salt lost by sweating, and from the conditions created by the CF itself.

I got all the early childhood maladies—chicken pox, mumps, measles, colds—but came through in pretty good shape after each battle—glad for the opportunity to pick up where I left off with friends and my younger brother. I hated catching the occasional cold or bout of fever, but always at the tail end of each, I could easily rumble all that extra-gunky mucus up and out of my lungs as I got myself back up to speed.

I liked wrestling and running, once I started junior high back in Illinois. But, thanks to Dad's career, we moved to California in 1972. I began fitness running and continued cycling through my high school years and beyond. Once out west, I added hiking and backcountry trekking to my "do often" list, completely amazed by the diverse variety of landscapes up, down and across the state—this was no longer the flat Midwest of my childhood!

After high school, I held a variety of full-time jobs after moving out from the folks' house. I always loved nature, but wistfully realized bad weather and CF might not mix very well. So I dove into another of my main interests—art—specifically, graphic design (leading eventually to book publishing). I gained employment at a software company.

I also enrolled in college. My education was paid for, since my studies dovetailed with my job position in the art department. I married; earned a degree in 1986, and received my engraved five-year brass plate before tendering my resignation to the corporate world in 1988. Freelance design and desktop publishing was my next path.

> "I've just been damn lucky—but damn grateful and appreciative each year as my life's long, winding road of adventures has unfolded."

My wife and I sold our small house in suburban Los Angeles and moved to the Sierra Nevada foothills, where we built our new home in 1989. Things went south quickly and our marriage dissolved. The divorce *(ouch!)* was final in 1994.

To preserve my sanity, I carved a meandering trail through waist-high pasture grass, around blue oaks, along the fence lines of the property, and started running again every morning. I also began hiking more in the oak woodlands surrounding the property, re-discovering a wondrous world of exploration! For a time, while freelancing, I was able to juggle a part-time position outdoors as a naturalist, teaching sixth graders the life-cycle of trees and composting. This was an immensely rewarding experience at this particularly bittersweet time.

For years, my sole source of lung clearance had been my activity level. Besides running and hiking, I had a Nordic Track on which I started each day, when Cheri and I lived in L.A. But, by 1986, *Pseudomonas aeruginosa* made its first appearance in my lungs. There was no time for pessimism. After several more visits to the CF clinic, I began inhaling albuterol, Pulmozyme® and using a vest. Still, I wondered—*what else could I do for myself?* I knew adequate hydration was imperative, so I increased my daily water intake significantly.

I had kept a pair of ten pound iron weights my Dad had skewered with small sections from an old hickory broomstick. I added these to my bare bones treatment routine as free weights every time I used the vest, which I always did standing, for increased lung capacity. I also began doing push-ups for more upper body strength. I could barely squeeze off ten when I started, but that improved quickly.

I first took cipro orally in 1996, graduating to inhaled tobramycin to improve my PFTs. Hospital and home IVs were new additions. Then, I was diagnosed with CF-related diabetes in 1998. This could have been added to a growing list of "end of the world as I'd known it" moments. But again, not much room for pessimism. Thanks to insulin use, my metabolism worked

Continued on page 22

Optimistic Is My Middle Name

By Nicole Matthews

Optimistic is defined as: "disposed to take a favorable view of events or conditions and to expect the most favorable outcome", or in normal words: looking to the brighter, more beautiful side of things. I believe I am the type of person who is always optimistic, or at least tries to be. The glass is always filled, either with fluid or air - it's filled to the top. Yes, I have CF, a gluten allergy, scoliosis, rheumatoid arthritis, major sinusitis, and who knows what else, but I am breathing, and I am living.

I go to work Monday through Friday, volunteer every Saturday with SABAH and Gliding Stars (ice skating programs for people with a handicap). In my spare time I am volunteering as an EMT and Corresponding Secretary for the Hillcrest Volunteer Fire Company. And finally, after all that, I spend time with my boyfriend, Michael, and my family.

Smiling is my specialty. I know if I smile at one single person and he smiles at someone else, I have started a smiling chain. I may be hurting inside, but I try my best to not have people see that side of me. I have my days where my bones and muscles hurt so bad that I can barely move; or I cannot stop coughing or leaking disgusting fluids out of every orifice of my face, but I put that smile on. I want them to see the "Optimistic Nicky" no matter what obstacle is in my way for that day.

I have been optimistic for as long as I can remember. I believe I am that way because of my parents, Ernie and Connie, and my little sister, Katie. They've helped me live every day to its very fullest, always took a vacation, never wasted a minute, and always had that helping/caring hand. They helped me see that things can be tough, but with our family's love we can overcome it and help each other with whatever life throws our way.

> "Smiling is my specialty. I know if I smile at one single person and he smiles at someone else, I have started a smiling chain."

Having CF makes me that much stronger; it makes me a better person in some way. I would not change my health for any reason; well, I wouldn't mind getting rid of the gluten allergy, though. (LOL.) CF has made me realize that things could be worse the next day. So take this day in, each breath at a time, appreciate the minute you're in now, because truthfully I do not know what tomorrow is going to look like. And that is the only pessimistic side of me and, I believe, of any CF patient.

Working as an optimistic person can be pretty tiresome, but it is worth it. My coworkers and friends always ask how I stay so positive. I truthfully don't know how I do it; I just know it could always be worse. I could have more health problems. I could be alone in the world. And anything else is possible. I am blessed with what I have in life, and that includes: my huge amazing family, my boyfriend, Michael, and his family, my pets, my job, my coworkers, my friends, my apartment with Michael, my huge heart and my health.

I would not change who I am any day. I love being optimistic, and I love looking into the future with arms wide open and a smile on my face. If you are not optimistic you should try it for a bit. It's tiring but totally worth it. Smile and always remember to breathe in deep. ▲

NICOLE MATTHEWS AND MICHAEL KOWAL, JR. AT 30-MILE POINT LIGHTHOUSE IN BARKER, NY.

Nicole is 24 and has CF. She and Michael live in Orchard Park, NY.

Picnic

PHOTO BY PHILIP HOWELL

Welcome to my picnic.
Only to no picnic you've been.

May I offer you sterile saline, distilled water, or even boiled tap water?
Whatever you like. Your sinuses will feel like new.

Will that be with one, two or three heaping teaspoon fuls of sea salt? Whatever you like. Some like a little baking soda added to quench the saltiness.

It's your choice.
Only it's not mine.

Welcome to my picnic.
Only to no picnic you've been.

May I offer you a 1cc sinus flush, three times daily of Tobra, Cipro, or even Coly-Mycin? Whatever you like. A little sting in the sinuses and you'll feel as good as new.

It's your choice.
Only it's not mine.

Welcome to my picnic.
Only to no picnic you've been.

May I offer you something else? Perhaps some Nasalcrom or Flonase or would you prefer a pill like Clariton? Whatever you like. A little more medication won't hurt you.
It's your choice.
Only it's not mine.

Welcome to my picnic.
Only to no picnic you've been.

I feel I'm at the Mad Hatter's tea party in Alice's Adventures in Wonderland. Only to no picnic I've been. Instead of tea and cake, I am offering what has kept my sinuses from getting worse.

If I keep my sinuses healthy, my lungs will remain healthy.
No post-nasal drip will infect my lungs. That's in theory.

I still get sick even when I do take care of my sinuses.
I am obligated to myself to continue this regime no matter how uncomfortable it is. That's life, I suppose.

It's your choice.
It's my choice, too.

Welcome to my picnic.
Only to no picnic you've been.

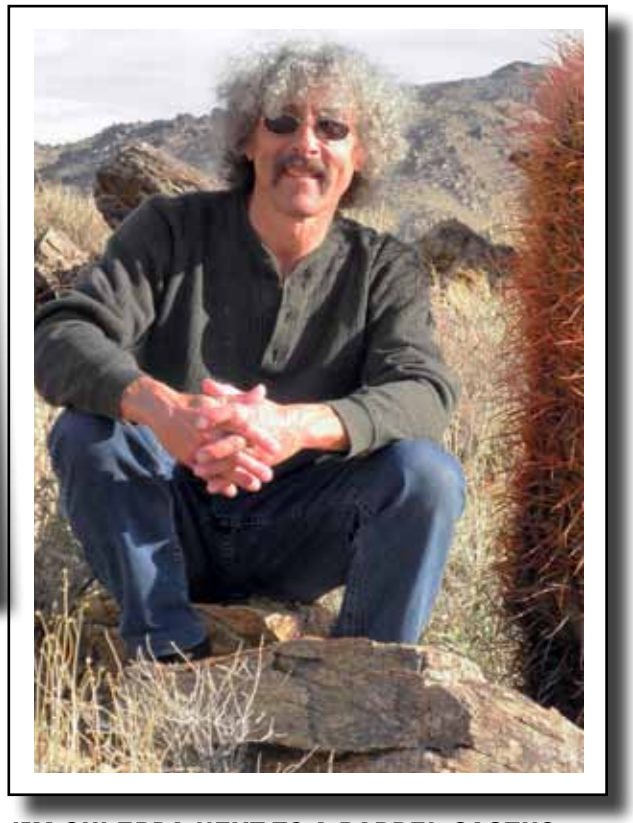
-K. Bischoff-Howell, 1998

"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...

EVAN BURTON (RIGHT) AND HIS BROTHER, SPENCER (LEFT), IN THE OREGON WOODS, 2008.

ANA STENZEL, KATHY RUSSELL AND ISA STENZEL BYRNES AT A SHOWING OF "THE POWER OF TWO" AT THE HOLLYWOOD THEATER IN PORTLAND, OREGON IN NOVEMBER 2011.



JIM CHLEBDA NEXT TO A BARREL CACTUS NEAR THE TOP OF RYAN MOUNTAIN, JOSHUA TREE NATIONAL PARK.

RADIE STROUD

MARIA FIOCCOLA

NICOLE MATTHEWS AND MICHAEL KOWAL, JR. AT THE CYSTIC FIBROSIS "BREATH OF LIFE GALA".

25th National Cystic Fibrosis Family Education Conference

Facing CF Together With Confidence!

Sofitel San Francisco Bay Area ■ Redwood City, CA
July 27 - 29, 2012

Connecting Families, Care Teams and Scientists

Partial List of Speakers:

Michael Boyle, M.D., Director, Adult Cystic Fibrosis Program, Assistant Professor of Medicine, The Johns Hopkins Medical Institutions, Baltimore, MD
Eric Olson, Ph.D., Vice President and Program Leader, Vertex Pharmaceuticals, Inc., Cambridge, MA
Felix Ratjen, M.D., F.R.C.P.(C), Division Chief, Respiratory Medicine, The Hospital for Sick Children, Toronto, Canada
Heather L. Walter, Ph.D., Mother of a child with CF, Parent Mentor, CF Family Council, Akron, OH

For more information: 650.404.9975 www.CFRI.org

CFRI RetrEAT Nourishment for the Soul

CFRI Teen and Adult Retreat

July 29th - August 5th, 2012 ■ Vallombrosa Center
Menlo Park CA

Meet some great friends.
Learn more about CF self-care.
Feel that you're not alone.
Experience a place for hope and healing.

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: $85 per person for the entire week. Daily fees are $15 per day for visitors or $10 per meal. 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!
For more information: 650.404.9975 www.CFRI.org
http://www.facebook.com/home.php#!/group.php?gid=2342719557

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

Jennifer Hale
South Pasadena, FL
40 on January 29, 2012

Arthur Herron
Sacramento, CA
30 on September 13, 2011

Adrienne Schweizer
Oregon City, OR
20 on October 9, 2011

Wedding

Kathy & Paul Russell
Gresham, OR
47 years on March 27, 2012

Information from the Internet...

Compiled by Laura Tillman

This issue brings a potpourri of articles from the Internet

TREATMENTS

The revival of fosfomycin. Argyris S. Michalopoulo, Ioannis G. Livaditis, Vassilios Gougoutas.

International Journal of Infectious Diseases, Published online 26 September 2011.

There are three forms of fosfomycin: fosfomycin tromethamine (a soluble salt), fosfomycin calcium for oral use, and fosfomycin disodium for intravenous use. It is highly active against Gram-positive pathogens such as Staphylococcus aureus and Enterococcus, and against Gram-negative bacteria such as Pseudomonas aeruginosa and Klebsiella pneumoniae. Fosfomycin is well tolerated, with a low incidence of adverse events.

http://tinyurl.com/6hz6ttu

Fosfomycin Enhances the Active Transport of Tobramycin in Pseudomonas aeruginosa. David L. MacLeod, Jyoti Velayudhan, Thomas F. Kenney, Joseph H. Therrien, Jennifer L. Sutherland, Lynn M. Barker and William R. Baker. Antimicrobial Agents and Chemotherapy. March 2012 vol. 56 no. 3 1529-1538

The data demonstrate that fosfomycin enhances the uptake of tobramycin, resulting in increased inhibition of protein synthesis and ultimately bacterial killing.
http://tinyurl.com/88vfrhz

Clarithromycin therapy for patients with cystic fibrosis: A randomized controlled trial. Robinson P, Schechter MS, Sly PD, Winfield K, Smith J, Brennan S, Shinkai M, Henke MO, Rubin BK; Pediatric Pulmonology (Jan 2012)

Two previously reported short term, open label trials of clarithromycin in small numbers of patients with CF failed to show significant benefits in modifying lung function or inflammation. An international double blind, cross-over trial in which 63 subjects with CF were studied while receiving either placebo or 500 mg oral clarithromycin twice daily for 5 months, with a 1-month wash-out was performed. No significant difference in either the primary efficacy end point or any secondary end point was seen during the period of clarithromycin treatment compared to those seen during placebo administration. We conclude that clarithromycin is not effective in treating CF lung disease.
http://tinyurl.com/6s5uzfc

International phase III trial of liprotamase efficacy and safety in pancre-

Continued on page 25

more efficiently than ever before. And, for the first time in my adult life I was able to gain and hold significant weight. I went from 128 spindly pounds to a more solid 138. I also discovered that by monitoring my blood glucose level, I now had an early warning system showing me that consistently elevated sugars meant the *Pseudomonas* in my lungs was gaining ground.

When I connected with the CF team at Stanford University in 2004, my PFT results resembled stock market zigzags when charted on a visual timeline I sketched out. Thanks to a bronchial arterial embolization, followed by my FEV1 plummeting from 60% down to 25%, and a letter from one of the clinic physicians, I qualified for SSDI (Social Security Disability Insurance) in 2007. I was finally able to stop working and focus on increasing my post-embolization lung capacity. *Another blessing!*

By 2008, the alien invader in my lungs was now completely resistant to tobramycin. Celestin (colistimethate) became my inhaled antibiotic of choice, every other month. In June 2009, I had another three-week "staycation" with PICC line cocktails at Stanford. My docs expressed rising concern about what were now crackling lower lobes in both my lungs—what I referred to as my "compost piles". I did a lot of walking and deep breathing outside in the fresh air between doses and PT, pondering how I could again adjust my self-reliant approach for better results.

Trendellenberg tilt-bed lung clearance therapy, a fixture with every CF hospitalization, kept swirling 'round in my brain. Once back home, I bought an inexpensive inversion machine at a sporting goods outlet in California's North Bay region, where I now lived. For core strengthening, I added several standing yoga positions. And, the best mother-in-law in the universe gave me a pair of five-kilo dumbbells to replace the ol' hickory sticks. All are utilized while I wear the vest and do my nebulizer treatments simultaneously, making quite a frenetic image, I'm sure. But, in addition to cycling, I had managed to fine-tune my home treatments to regain the vigorous level of overall fitness I'd always enjoyed, and now with a more consistently satisfactory FEV1 level! I was gratified my efforts paid off—my "compost piles" went silent, not nearly as foreboding as they had first seemed.

> "Negative energy (*i.e.* pessimism) is wasted energy, and certainly does not lend itself well to my optimism index."

Shortly after the FDA finally approved aztreonam (Cayston), I switched to it every other month to keep the *Pseudomonas* at bay. I wanted to keep my powder dry, and not yet alternate each month between colistin and Cayston. After consulting with my Stanford docs, I switch back to the colistin alone every other month for a while to increase the chances that my alien invader *will not* develop a resistance to either drug too quickly; then shift back to Cayston. Embrace it all and move forward—there is no rewind button for the life we each are handed.

Now "speeding past 50" myself, with PFT numbers hovering in the mid-50% range, I may have slowed down a bit, but don't think I can or should complain about much of anything. Negative energy (*i.e.* pessimism) is wasted energy, and certainly does not lend itself well to my optimism index. I'm still functioning with my original equipment (*i.e.* my own lungs) and am holding steady. If this keeps up, I'll be too old to get placed on the transplant list.

Wacky liver numbers have appeared as the years have sailed by—possibly CF-related liver disease in the pipeline? Such are the woes of advanced age with CF. These days, I still look forward to a fine ale with friends, once every blue moon. They are savored more than ever since they are now so rarely enjoyed.

Oh, and yes—my bones ache every now and then. And *jeez,* I'll probably need to get my prostate checked soon; maybe even a colonoscopy?! And, all those miles on my feet have earned me some gnarly bunions—but again, that just might be my genes. On the bright side, years ago when I wore contact lenses, I began using bottled saline solution to flush my sinuses. I continue flushing, but single use 0.9% sterile saline ampules from the hypertonic solution I mix for treatments now keep my sinus airways happy. I can easily carry a few extras along in my pocket.

I harbor no illusions as I reflect on life with CF—it's been no walk in the park. My spontaneity index has shrunk with age. Oftentimes, disillusion and disappointment go hand-in-hand. However, three ***BIG*** lessons I learned early are: *1)* live fully in the moment; *2)* maintain a sense of wonder in my daily encounters; and *3)* never lose my sense of humor. With an optimistic outlook, innate self-confidence and the peace of mind engendered by both, I've been able to get through most anything I have encountered due to setbacks from CF—or most anything else.

The life lessons of love and loss may be right around the next corner. Our family lost our youngest sibling,

Cathy, two months before her 21st birthday in 1985. The previous year, we had all gathered to celebrate my first wedding—Cathy and our younger brother, Mark were in the wedding party. Then we lost Dad in 2000—he and I share the same birthdate, so each year he is gone is yet another bittersweet reflection.

Conversely, Rolly and Ken, two of my dearest and best-loved friends from high school, both are gone now. Rol, best man at my first wedding, was killed by a bolt of lightning in August 1989; he never knew what hit him. Ken, best man when I married a second time in 2004, lost his life after being catapulted over a truck that collided with his motorcycle—exactly one month to the day after he and his wife did a stunning guitar and mandolin duet at wedding number two. Ken and Rolly were vibrant, healthy men; both left young families behind. I'm still here with CF—*what's up with that?* Perhaps the insightful discovery I first gleaned as a young boy has a lot to do with it.

After divorce number two was final in 2009, I exhaled a massive sigh of relief. Then, I began focusing in earnest on my next road less traveled. I bought a home in March 2010, down in the high desert region of southern California, directly adjacent to Joshua Tree National Park. For the first time in decades, I live in closer proximity to my sister, Karen, her family and our dear Mom. Due west on the distant horizon is the high ridgeline of the San Bernardino Mountains, most days an effective barrier to the majority of SoCal smog. Just as important, a new world of extraordinary hiking opportunities beckons just outside my door! The low humidity, high desert breezes and moderate 2500' elevation complement the treatment regimen I continue to tweak as the years stretch on.

I published two last books in December 2010; deadlines are now ancient history. As seasons in the desert allow, I am fascinated when hiking—discovering falcon nests, cacti and wildflower blooms or creatures to photograph for sketching studies and painting. With my past construction experience, I've been tuning up my "new" desert dwelling and art studio. I also spend more time playing and picking on my acoustic guitar, in memory of my dear friend, Ken. It was he who turned me on to finger-picking and was with me when I bought my guitar in our final year of high school, so many moons ago. And that hair I got from Grampa Ziggy—it's still incorrigibly curly, and turning a lot greyer with each passing year. Life's as exhilarating as it is tumultuous. It is—has been—bittersweet—but good.

My pursuit of a healthy, fulfilling life continues with undaunted zeal as I stare down 55. Fear is the darkroom where negatives are developed—I'm sticking with radiant optimism! I could not have gotten this far without it. ▲

James is 54 years old and has CF. He lives on the edge of Joshua Tree National Park in CA. He is untethered, relatively unfettered, gainfully unemployed and can be contacted at: james@back40publishing.com.

Benefactors

BRONZE

Annina & Greg Briggs
David Ebacher
David Lantz
Kathy Russell

SILVER

Jill Doran

GOLD

Alice Todd & Cheri Dewilde
(in memory of Tina Williamson-Crow)

PLATINUM

Gilead Sciences

Those who give $50 or more in a year will be recognized as Benefactors, unless they request anonymity. The categories are: $50-$249 Bronze Benefactor, $250-$499 Silver Benefactor, $500-$999 Gold Benefactor, $1,000 - $4,999 Platinum Benefactor.

Donations over $15 are tax deductible. Please make checks payable to USACFA, Inc.
Send donations to:
USACFA, Inc., P.O. Box 151024, Alexandria, VA 22315-1024

I Am An Optimist

By Mark A. Levine

Negativity is not in my vocabulary. I just don't have the energy or the patience for it. Plus, I hear it's not really good for your health. And you know what? That's what I choose to believe, so if you have any data to the contrary, I'm not really interested.

Optimism. Now we're talking. That is where the future lies. To me it's all about being positive, seeing the bright side of things and living life with a sense of hope.

What's my story in a nutshell? Here it is. I was diagnosed with cystic fibrosis (CF) at the age of two. My brother David was born five months later with a much more severe case of CF. He died at the age of 21, three years after a heart/lung transplant. Like many with CF, I do my daily breathing treatments, cough a lot and take pills when I eat. I also go on IV antibiotics when I need it.

I'm sure that people in similar situations might be all bummed out and ask, "why me?" I mean, I watched my brother die young fighting the very same disease that I was struggling with every day. My prognosis was not good when I was first diagnosed back in 1970 and, statistically, I am now living on borrowed time, since the median age of someone with CF is just under 38 and I am in my early forties. What's so positive about that?

Here's the deal. I don't ask those negative questions. They don't get me anywhere and would only make me second guess the actions that I do take to live life to the fullest and stay healthy. Plus they would get in the way of more important questions like, "What's for dessert?"

I'm sure you've read posters and heard people say, "It starts with the right attitude". Perhaps you have heard the saying, "If you think you can or think you can't, you're right," meaning that it all starts in your head and with your belief system. The thoughts you have and choices you make control the game.

Let's face it. Optimism is a choice. I can choose to be optimistic or not. The choice is not based on my circumstances unless I accept that I'm a victim of my own life. There are things that I can control and things that I cannot. I figured that out a while ago and decided to move on.

To explain why I think this way, I want to share with you a book titled The Slight Edge, by Jeff Olson. It is a fantastic read and helped put into words one of the philosophies by which I live my life. The Slight Edge was a new book to me a couple of years ago but the concept was not. I've lived by Mr. Olson's philosophy to some extent since I was a little kid. In my mind it sounded like this, "Do the right things in your control and the good things will happen."

And they did. To outsiders, these things may seem like luck. Heck, to me they sometimes seemed like luck. However, as easy as it was to convince myself otherwise, it wasn't just random luck or good fortune. There has always been more in play.

> "To me it's all about being positive, seeing the bright side of things and living life with a sense of hope."

MARK LEVINE

If you've ever met the right person at the right time or got that promotion out of seemingly nowhere, it's probably because you set yourself up for success. Sure, things do just happen, both good and bad. But doing the right thing, day in and day out, puts the odds on your side and sets you on the right course even if you didn't plan it out that way.

I'm sure you have heard of the phrase "Carpe Diem!" or seize the day. I like to believe that I live like that. But I also know that I cannot ignore the future. Truth is, what I do today greatly impacts the future. Here's an example:

Every day, twice a day, I spend 10 minutes inhaling salt water (technically it's called 7% hyper-tonic saline

solution... but it's really just salt water). I've been doing it for years now. The first time I used it, I'm sure I coughed quite a bit. But I'm also sure that I didn't feel incredibly different after the first treatment and I know my lung function did not increase dramatically that instant. So why continue?

The answer to that question is easy. Doing my salt water breathing treatments is within my control and is the right thing to do. Over the long run, those simple treatments may add up to be the very reason for me maintaining my health or keeping me out of the hospital.

Bottom line, I trust the system and I'm optimistically hopeful. (OK, I also do my own research and consult my doctor, but you get the point.) When the system recommended inhaling salt water twice a day, I had a choice. I could have decided to do it or not. I decided that I would do it and that in the long run, I would be making an impact on my health. So I figured out how I was going to do it. And then I started doing it. End of story.

I try to do the right thing - every day. And when I do that, I have no reason to be anything but optimistic.

In the long run, it will pay off - most of the time. As with anything, there are no guarantees. Sure it's easy to get talked out of doing the right thing. After all, the right thing doesn't always pay dividends instantly. Think of the person who joins the gym only to quit three weeks later because he didn't see results. Sounds crazy, but it happens all the time. Think of this, though. Imagine if you worked out every day for ten years. Think you'd see and feel a difference? You absolutely would.

How about if you saved $100 a month? Would you be rich at the end of a year? No way. But after a few years you might notice an emergency fund forming or even a nice nest egg for a well-deserved vacation. There's an excitement that comes with doing the right thing and I love that feeling.

Having a plan for today, which also encompasses the future, results in hope and optimism. In the end, when I do the right things that are in my control, the only thing I can do is smile. ▲

Mark is 42 and has CF. He is a Director of USACFA. His contact information is on page 2.

TILLMAN *continued from page 21*

atic-insufficient cystic fibrosis patients. Drucy Borowit, Christopher Stevens, Lee R. Brettman, Marilyn Campion, Barbara Chatfield, Marco Cipolli, for the Liprotamase 726 Study Group. Journal of Cystic Fibrosis. Volume 10, Issue 6, Pages 443-452, December 2011

Most cystic fibrosis patients have exocrine pancreatic insufficiency (EPI) and need supplementation with pancreatic enzyme replacement therapy (PERT). Liprotamase, a novel non-porcine PERT containing highly purified biotechnology-derived lipase, protease, and amylase, has successfully undergone initial efficacy and safety testing. This trial demonstrated that liprotamase at a fixed dose of one capsule per meal or snack (5 capsules per day) was well tolerated and significantly increased fat absorption, significantly increased protein absorption, and significantly decreased stool weight.

http://tinyurl.com/76tkdz3

Oral antimicrobial use in outpatient cystic fibrosis pulmonary exacerbation management: a single-center experience. Elissa Charlotte Briggs, Thuan Nguyen, Michael Abraham Wall, Kelvin David MacDonald. The Clinical Respiratory Journal. Article first published online: 9 AUG 2011. DOI: 10.1111/j.1752699X.2011.00246.x

The observations suggest that one course of oral antimicrobials is frequently effective in outpatient cystic fibrosis (CF) pulmonary exacerbations, but exacerbations requiring more than one course of oral antibiotics are likely to require intravenous (IV) therapy.
http://tinyurl.com/76dhjso

FYI

Bile acids in sputum and increased airway inflammation in patients with cystic fibrosis. Ans Pauwels, M.Sc., Ann Decraene, M.Sc., Kathleen Blondeau, PhD, Veerle Mertens, PhD, Ricard Farre, PhD, Marijke Proesmans, MD, PhD, Pascal Van Bleyenbergh, MD, Daniel Sifrim, MD, PhD and Lieven J. Dupont, MD, PhD. Chest. Published online before print December 1, 2011, doi: 10.1378/chest.11-1573

Bile acids (BA) are present in sputum of more than half of cystic fibrosis patients, suggesting aspiration of duodenogastric contents. Aspiration of BA was associated with increased airway inflammation. In patients with bile acids aspiration, the levels of bile acids were clearly associated with the degree of lung function impairment as well as the need for IV antibiotic treatment.
http://tinyurl.com/c937gxy

Two More Pancreatic Enzymes

Continued on page 29

heart." Of course this is ridiculous! Raising kids is a process that is enjoyable (mostly) and adds incredible fun and flavor to life. You don't do it for an end result. Exercising regularly is the same. You do it for the process, not the goal. Now I am a goal driven person, so this took me a very long time to understand. But as soon as I drop the "goal" of an exercise program, and simply focus on enjoying the process of moving, the ups and downs of CF exacerbations don't matter as much.

Of course there are many long-term benefits of regular exercise. But when setbacks happen, and they will, it is better to focus on the assists accrued during and immediately after a workout, because whatever your fitness level, these things hold true.

For example, it certainly seems easier to clear my lungs during and immediately after exercise, and I know that others with CF have this same experience. The natural shaking that occurs with physical movement is likely a reason for this, as is the higher ventilatory rate and volume.

Interestingly, CF researchers are now showing that exercise may also alter ionic flow across the lining of the airways, thus increasing the airway surface liquid. But any of us could have told them this years ago (OK, we probably wouldn't have phrased it exactly like that). The end result of a good run or bike ride or anything that gets your heart and lungs pumping hard for an extended amount of time is the same as breathing hypertonic saline or Pulmozyme - thinner mucus that is easier to clear.

Additionally, the mood elevation and creation of the neurotransmitter balance in the brain that is so healthy happens during and immediately after movement. Your lungs and brain don't care if you hit your 5-mile goal, or finish your round of P90X. It also doesn't matter to them how many times you have to "start all over". They just like to function better, and exercise can definitely help them with this.

Here's another common complaint (negative view) about exercise: It's so embarrassing to exercise. I can't do anything I used to be able to do, let alone look halfway fit if I work out with friends. Exercising alone is boring, and people look at me like I'm dying if I go out in public.

> *"The one perfect workout is the one you will do, and if that means that, like me, you get interested in a new thing every two months, so be it."*

This is a tricky one to deal with because it is all about pride. I get this. It can definitely be embarrassing to compare myself to someone else. For instance, when I am out "running" and coughing (because those two things always go together) and an octogenarian on her powerwalk passes me talking on her cellphone, it is easy to choose embarrassment and shame. But here is the thing: no one else lives with my genes or in my jeans, and the same is true for you. Not even my sister, Kathy, or my brother, Tom, had the same combination of my CF mutation, modifier genes, and environmental influences. This is true of every living organism. There is no comparison to make. And if there is no comparison to make with my own siblings, I certainly shouldn't compare myself with a very fit and talkative octogenarian! We all do this. It is a natural thing for a brain to do. But you don't need to believe that it is "bad" to be different from others.

It is also very hard not to compare what I can do today with what was possible years ago. But what is the point of doing this? Aging happens. In the case of living with CF, this should be good news, right?

What about the reactions of other people? How can you avoid those? This one has been tougher for me. Having lived most of my life worried about what everyone else thinks, it has finally dawned on me that this isn't the best idea. First of all, 99.99% of the time no one else is actually thinking anything about me. They are usually considering their dinner options or wondering what others are thinking about them. Sometimes, though, I get the "look" from someone at the gym when I cough. This used to really bug me, but why should it? They have no clue what I live with, and have no basis on which to judge me. If they are worried about catching something and actually say something to me, I will assure them that I am not contagious and go on with my workout. Other than that, I now choose to ascribe their "look" to indigestion, and move on. It is time to get thick skin, and get a bit selfish. If you are not contagious, then don't let them scare you. If you are, go home.

Another common negative attitude regarding exercise is the following: Who in the world has the time to exercise? On top of everything else I have to do…are you kidding me? Why would I waste any of the few free hours a day I have exercising? They want me to suck on this nebulizer for two hours, shake another hour, and then exercise on top of that? Right. When?

This way of thinking is hard for me to relate to, I must admit. For some reason, I have always *had* to exercise. It

has almost been a compulsion. The day feels "wrong" if I haven't worked out in some way, even if that means just going out for a walk. I get downright depressed if I have to go for an extended period of time without it. Thus, exercise is not a choice for me; it is life. This is why I've titled this article as I have. No more do I exercise to stay or become "fit". I do it to stay alive. I do it because I know it helps with my lung function. So just as breathing saline, Pulmozyme, antibiotics, wearing a vibrating vest, and taking copious enzymes with food is "life" for me, so is exercise. I encourage you to take on this attitude. It has served me very well. It is in part why I have remained healthy—along with a good dose of luck and an awesome modifier gene or two.

The other thing to remember is that exercise is not all about the lungs! It helps improve so many areas of life that everyone benefits from it, CF or not. I like to think about the time I exercise as investment in my high-quality-of-life savings account. Very sound research has shown that exercise helps with mood, depression, anxiety, stress reduction, body image… all common problems in people with chronic illness. Not only that, exercising regularly simply makes it easier to do normal activities that go along with living in today's world. Simply put, staying as fit as possible makes life easier and more enjoyable. To me, that is worth the investment.

So when your negative gremlins start chatting in your head about the worthlessness of exercise, remember that you have a choice of what to believe. Actively argue with them (just don't do this in public), and choose the upbeat outlook. ▲

Julie is 51 and is a physician who has CF. She may be contacted at: jdesch@usacfa.org.

Be sure to check us out on:

Twitter: http://twitter.com/#!/cfroundtable

Facebook: http://www.facebook.com/CFRoundtable

Blogspot: http://www.cfroundtable.com/blog-2/

CLUB CF ONLINE

The focus of Club CF is: LIVING BREATHING SUCCEEDING. Club CF wants those who have CF or are affected by the disease to see that, despite all the challenges that come along with cystic fibrosis, it is possible to live a happy and successful life.

Club CF shows how people in different age groups (20+, 30+, 40+, 50+, 60+, caregivers) are succeeding. Through Club CF, people can give hope and inspiration to those who are hesitant or nervous about what lies ahead of them.

People with CF are succeeding and making a difference in the world in high school, college, sports, careers, relationships, starting a family, post transplant, and disability. If you are one of the many people who are LIVING BREATHING SUCCEEDING, join Club CF and show the world what you have done! To learn more, please visit us online at: www.clubcysticfibrosis.com

Club CF is sponsored by The Boomer Esiason Foundation, which is committed to showing the world that people with CF are living longer & fuller lives, and by generous support from Genentech.

COUGHING WITH A SMILE...

Hey, At Least The Glass Has Something In It!

By Jennifer Hale

Hello again readers! I hope this edition of *CF Roundtable* finds y'all embracing spring and the warmer weather that is approaching. So the topic this time is "Am I A Pessimist Or An Optimist?" Is the glass half empty or half full? As you can see from the title of this column, I think sometimes one has to just be glad there is *any* liquid in it at all. Life is not perfect and dealing with CF is anything but perfect.

According to Amy Grant, "Sometimes the greatest act of faith we can muster is just putting shoes on in the morning." When I read this quote, I could really relate to it because, sometimes for those dealing with CF, that is about all we have. I find that to be okay. Some days are going to be better than others. Growing up, I was taught to be a fighter - confront each battle with CF and keep myself as healthy as possible to win the CF war! I find in the forty years I have been battling CF, I take this optimism with me for each challenge in my life, whether it be CF-related or not.

Amy Grant also once said that, "Nothing stays the same, even if we want it to and, thankfully, especially when we don't." How true is this? When I am feeling bad I want that to pass quickly! Luckily, health and circumstances do change so that I can get better when I am ill and stronger when I am healthy. Hey, that sounds like an optimist! I told myself recently on the good days I should go for it and on the bad days I will just work through it. That has really helped me this past year or so.

My health took a grave turn in 2011 and I am still battling the residuals from that year. It is hard to always be optimistic when nothing is going your way and you are not feeling well, no matter how hard you are trying. CF is unpredictable and I find over the years I have had to adjust my sails. A Facebook friend of mine recently posted a quote that said, "The pessimist complains about the wind, the optimist expects the wind to change and the realist adjusts the sails."- Anonymous. When I thought about this quote I felt it was very true. I do think about the worst possible scenario in a situation, but then I go right on adjusting my sails so I can deal with the different outcomes and stay positive that the light will shine at the end of the tunnel. I tend to approach all problems in my life like this, and I really feel it is because I have CF and had to deal with it from a young age.

> *"Luckily, health and circumstances do change so that I can get better when I am ill and stronger when I am healthy."*

JENNIFER HALE

I was diagnosed at the age of two and spent my fair share of time in the hospital for "tune ups" while missing out on school events and other events in my adult life. I find that in dealing with CF there are a lot of complications and different conditions that arise from having CF, whether it be CFRD, CF-related arthritis or gastrointestinal problems – just to name a few. I always have to weigh out possibilities and outcomes.

Unfortunately, when dealing with a chronic illness, bad things happen and I find my first thought is to prepare for the worst case scenario but then to stay optimistic and fight all the way through - to keep adjusting the sails but to be aware that a storm can come in and blow me off course. Then I adjust the sails again and again!

I don't feel that because I review the worst case scenario in a situation it means I am a pessimist. It is just how I process through a problem. I need to know all the outcomes - both the good and the bad. And I keep the bad out-

come on the back burner but keep stirring the pot of the good outcomes. I feel this comes directly from living with CF. I always need to know what is the worst that can happen, what treatment would be needed and, then, what we are now going to do about it. I like to know my options, but I focus and put energy in the positive option or, more importantly, the option I can control. I practice very hard not crossing the bridge until I come to it! So I feel I am an optimist and realist.

CF is part of me just like my brown eyes and my brown hair so I feel, of course, it is going to influence how I deal with all situations in my life. Dealing with a chronic illness makes one grow up real fast because one is faced with challenges and decisions beyond her years. I feel this has enabled me to be thoughtful in my decision making and able to deal with each curve ball of life. Life is messy, with or without CF. As preacher Joel Osteen once said, "Troubles are inevitable, misery is optional." I opt to not be miserable; it is a waste of time and energy.

I do have to say that being my own cheerleader all the time is tough. I have wonderful support from my husband and family but, in the end, it is up to me! It is up to me to do all my treatments and do all I can to stay or get healthy. I can't tell you how many times I have thought, "I wish I could just take a pill!" Welcome Kalydeco into the picture! The pharmaceutical companies have come a long way in creating CF drugs and will continue to keep surprising us old timers with new and exciting treatments. Optimism is at the doorstep of new technology and this new science is going to enable people with CF to live longer and/or more productive lives.

So, all in all, I think I am a *realist* with *optimistic* tendencies. Does pessimism rear its ugly head every once in a while? Of course; I am human, but I don't allow it to move to the front of the stove. It is on the back burner. It doesn't get the attention of a crafted meal on the front burner. I feel "circumstances can't dictate the way one lives; one must be stable in all the good and bad." This was said by Joyce Meyer, and being stable is what I strive for so that I can deal with all of it – "The Good, the Bad and the Ugly". Thanks Clint Eastwood!

Now I have to go drink my half glass of hot chocolate that is left. Thank you for the small things… ▲

Jennifer is 40 and has CF. She and her husband, Mark, live in St. Petersburg, FL. You may contact her at: jhale@usacfa.org.

TILLMAN *continued from page 32*

Approved by FDA

The Food and Drug Administration has approved two formulations of pancrelipase for different indications and patient populations. A delayed-release capsule formulation of pancrelipase, which will be marketed as Ultresa is to be used to treat children and adults with cystic fibrosis. The second pancrelipase formulation, which will be marketed as Viokace, has been approved in combination with a proton pump inhibitor. Both products are a combination of porcine-derived lipases, proteases, and amylases.
http://tinyurl.com/86h2oqf

Are measures of body habitus associated with mortality in cystic fibrosis. Andrew W. Fogarty, DM, J. Britton, FRCP, A. Clayton, DM and A. Smyth, FRCPCH. Chest. Published online before print February 23, 2012, doi: 10.1378/chest.11-2124

Lower muscle mass, shorter stature and a low body mass index are associated with increased mortality in cystic fibrosis. These measures of body build may contribute to the gender survival differences in individuals with cystic fibrosis.
http://tinyurl.com/6wk5e3z

PATHOGENS

Sputum candida albicans presages FEV1 decline and hospitalized exacerbations in cystic fibrosis. Sanjay H. Chotirmall, MD, Elaine O'Donoghue, MD, Kathleen Bennett, PhD, Cedric Gunaratnam, MD, Shane J. O'Neill, MD and Noel G. McElvaney, MD. Chest, May 2010

Airway colonization with C. albicans presaged a greater rate of FEV1 decline and hospital–treated exacerbations in CF.
http://tinyurl.com/2ufo7o2

Mycobacterium chimaera pulmonary infection complicating cystic fibrosis: a case report. Stéphan Cohen-Bacrie, Marion David, Nathalie Stremler, Jean-Christophe Dubus, Jean-Marc Rolain and Michel Drancourt. Journal of Medical Case Reports, 2011, 5:473

The authors observed that M. chimaera organisms contributed equally to respiratory tract infections in

Continued on page 29

IN THE SPOTLIGHT

With Evan Burton

By Jeanie Hanley and Andrea Eisenman

It's people such as Evan Burton, 27 years old with CF, who are so inspiring and make writing these articles for you out there such an honor. It is with excitement and tremendous pleasure we share Evan's life so far.

Evan is a musician (check it out at www.indubiousmusic.com) who had a bilateral lung transplant in 2011. He has maintained his optimism throughout the challenges. His life will hit home for anyone with CF in so many ways. We want to thank Evan for his candor in sharing his life and wish him even more success in the future.

EVAN PERFORMING WITH INDUBIOUS ON NEW YEAR'S EVE 2011, IN GRANTS PASS, OREGON, 5 MONTHS POST TRANSPLANT.

When were you diagnosed?

I was diagnosed at birth. My brother, Spencer, was 3 years old and had been diagnosed with CF so they tested me right away.

What was life like growing up in your house?

We grew up in the San Francisco Bay Area and lived there until about five years ago when we moved to Oregon. My brother and I were able to help each other throughout our life. Even though we have the same CF mutations, I was sicker than he was and he often was the one giving most of the help. Now that I'm post lung transplant, our situation is reversed. My two half-brothers and parents were also very supportive. My parents taught us at a very young age that we could do whatever we dreamed. They didn't buy into the predicted CF life expectancy of 18 years back then and stressed that life was about "mind over matter". Their positive outlook and encouragement provided a good foundation many years later for the positive conscious music of our band.

How did your disease affect you in high school?

Even though I felt fairly healthy I still had issues, primarily with my lungs, that led to many missed days. If I could go back I would have never done as many recreational drugs as I did in my teenage years and I would have started exercising, eating right, and doing my medications more strictly. We all think we are invincible when we are young, but I'm sure that if I would have done this I could have delayed or prevented my lung transplant. My carelessness may have contributed to my health decline which, at about 18 or 19, became increasingly worse. Back then I never would have thought that I would need to get a lung transplant, and I was 100% convinced that I would be one of the ones who overcame their disease, but sooner or later the reality sets in and there is nothing you can do to go back in time.

What did you do after high school? Is that when you started your career as a musician?

Around 16 years old, I became interested in playing music and taught myself the keyboard. My brother also played bass and since then we've been musicians together.

The band has been the focus since then and has grown so that we can support ourselves. Basically I eat, breathe, and sleep music. My brother and I both came into this life with an incredibly strong sense of purpose and even from a very young age we envisioned ourselves creating a band and changing the world. About five years ago, I moved from the San Francisco Bay area to Oregon and, in early January, moved into a new house.

What is your music and band about?

We're a 3-piece band called *Indubious*, with my brother on vocal and bass, me on vocal and keyboard, and our longtime friend, Matt, on drums. We write our own lyrics and music, which could be categorized as primarily Reggae, with a lot of other style influences such as funk, hip-hop, psychedelic, and jam band. We chose the name, *Indubious*, because it means "not doubtful" – being sure of yourself. Our music is designed to uplift people, trying to help them understand they have a mission and a purpose in life. So many people are unhappy and caught up in the dramas of everyday life that we forget to appreciate the little things. If we can breathe and have food, water, and shelter, then we already are so blessed and need to give thanks for these things!

When you are faced with your own mortality you realize that none of us

really truly have tomorrow, and that today might be the last day for any of us. When you make this realization you start to live in a different way and you are no longer waiting for happiness because it is right now! This does not mean abandoning your responsibilities or living carelessly but, rather, focusing your energy in the most effective way possible in order to manifest joy and love in yours and others' lives around you. By creating spiritual and positive conscious music, and spreading messages such as these in our lyrics, we aim to offer another perspective on life that might help people live to their greatest potential.

How has CF affected your music?

We have always viewed our condition as a blessing. Without CF we would have never come to any of these realizations and probably would have never made the growth possible to do what we do. I think life truly never gives you more than you can handle, and when you learn to handle what you get is when you get more of what you want! CF has given us an opportunity to walk what we talk. Somebody might say, "Oh, so you guys believe in all of this spirituality and positivity garbage; but what has it ever done for you?" I can just lift up my shirt, show them my scar and say, "It got me through this!"

The message of our music strongly embodies 'Love and Forgiveness'. This might also be in part to being so in touch with our own mortality that we realize how short life is and that there is truly no time for holding grudges or hateful feelings. It is through love and forgiveness that we can experience heaven right here on earth. When you hold onto a grudge, it's really the grudge that's holding onto you. One thing I can guarantee you is that when you get to the end of your life you will never say, "I'm glad I hated that person." You will look back at all of your worry, anxiety, hate, envy, and greed and see it as completely wasted energy.

How often do you perform and where?

We've been holding concerts for years and perform 3 – 4 times per month. Our venues are mostly in California, Oregon and Washington. In Oregon we have a huge, loyal fan base and perform many sold out shows! We have two CDs (Fresh Leaves, and Cosmic Seed) that are available on iTunes and are working on our third CD.

Has CF posed any obstacles as a musician?

Absolutely. Before my transplant, my breathing treatments were always a priority. Even so, I often became short of breath on stage while singing or dancing and we would have to end the performance early. It was tough for my brother to watch me suffer. Although he has CF, his lung capacity is high and he didn't have the issues on stage like I did.

Do you think your singing helped you out?

Yes! I believe that singing reduces stress and that it helps with physical healing. This was important before and after the transplant.

How did you feel after transplant?

The preparation for the transplant was intense and daunting at first. But looking back now it didn't seem that bad and I consider it now a blessing because I feel incredible. I have very high energy now, so during performances there's no shortness of breath and I can dance and go crazy!

Who is your inspiration?

My greatest inspirations are my parents who are both optimistic people. My amazing fiancée, Nicole, has always been a very inspiring and motivating force in my life and I could have never done this without her. I have always been inspired by the music of Bob Marley, The Beatles, not to mention the teachings of Gandhi, Jesus Christ, Amma, Emperor Haile Selassie III, Ram Das, Baghavan Das, and Paramahansa Yogananda.

Where do you see yourself in five years?

I would like to have expanded the band's reach into international markets like Japan, Australia, and Europe. Also, I'm engaged now and we have plans to start a family sometime soon.

Do you think there will be a cure for CF in your lifetime?

Yes! I believe that new medicines and research have added so many better options in treating CF. There is a famous futurist and brilliant scientist named Ray Kurzweil who made many predictions decades ago that were right on target about artificial intelligence surpassing that of humans', nanotechnology, and transcending disease through technology. He has a documentary on Netflix called "Transcendent Man" which I highly recommend. With drugs like VX-770 (Ivacaftor), and others on the horizon, it seems those technological cures will be here within a few years.

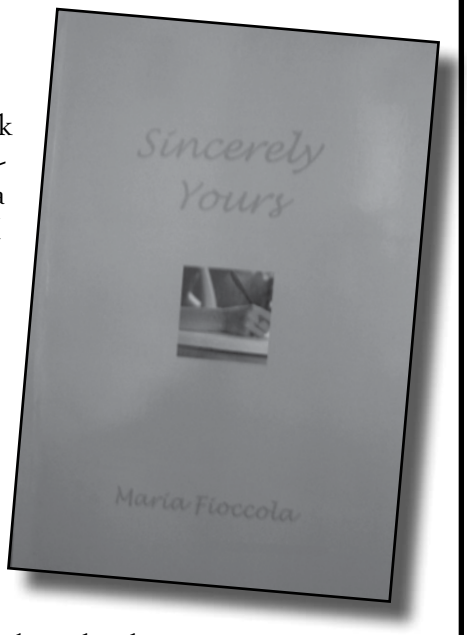
Any last thoughts?

Follow your dreams – life is too short. You'll regret it if you don't. You owe it to yourself and to the world to be happy and to give yourself the gift of reaching and living to your full potential. ▲

Jeanie Hanley is 50 and is a physician who has CF. She is a Director of USACFA. Her contact information is on page 2. Andrea Eisenman is 47 and has CF. She is a Director of USACFA and is the Executive Editor of CF Roundtable and Webmaster. Her contact information is on page 2.

If you would like to be interviewed for this column, please contact either Jeanie or Andrea.

CONVERSATION CORNER



I am Maria Fioccola. I was born in September 1984, at Oak Park Hospital in Illinois, where my sweat test was positive for cystic fibrosis. My childhood in Melrose Park, IL was rather normal. I went to a private school that didn't offer sports; however, I wasn't very athletic. I did join volleyball and basketball teams for several years at the township before entering high school. My family and I moved from Melrose Park to Lindenhurst after I graduated from the eighth grade. I attended Antioch Community High School where my CF took me for my first roller coaster ride at age 16. I did succeed and graduated a half year early and then attended community college for a year.

Since college, my life has gone many different ways. In the midst of everyday struggles, I always found time to write down my thoughts. Some thoughts were organized while others were not so much. I decided to gather all my thoughts and put them in some order. In the process, I have created my poetry book titled "Sincerely Yours".

"Sincerely Yours" is published with Blurb.com. You can search by title and order your copy today. Prices range from $11.95 to $27.95. All profits will go to the Cystic Fibrosis Foundation. Every donation helps.

Together Let's Make CF stand for CURE FOUND!!

TILLMAN *continued from page 29*

patients with cystic fibrosis. The authors believe that M. chimaera should be regarded as an emerging opportunistic respiratory pathogen in patients with cystic fibrosis, including young children, and that its detection warrants long–lasting appropriate anti–mycobacterial treatment to eradicate it.
http://tinyurl.com/5wqmzu2

Chronic Stenotrophomonas maltophilia infection and exacerbation outcomes in cystic fibrosis. Valerie Waters, Eshetu G. Atenafu, Juliana Giraldo Salazar, Annie Lu, Yvonne Yau, Larissa Matukas, Elizabeth Tullis, Felix Ratjen. Journal of Cystic Fibrosis. Volume 11, Issue 1, Pages 8-13, January 2012

Although cystic fibrosis patients experience a significant decline in lung function following exacerbation, chronic S. maltophilia infection and associated antimicrobial therapy do not affect subsequent lung function recovery.
http://tinyurl.com/6woqt2t

Prevalence and impact on FEV_1 decline of chronic methicillin-resistant Staphylococcus aureus (MRSA) colonization in patients with Cystic Fibrosis: A single-center, case control study of 165 patients. E. Vanderhelst, L. De Meirleir, S. Verbanck, D. Piérard, W. Vincken, A. Malfroot. Journal of Cystic Fibrosis. Volume 11, Issue 1, Pages 2-7, January 2012

In the authors' center the prevalence of methicillin–resistant Staphylococcus aureus (MRSA) in cystic fibrosis (CF) patients, chronically colonized with S. aureus and over the age of 4years, was 15.2%. MRSA colonization was shown to be associated with a genotype F508del, presence of bronchiectasis and hospitalization. The spirometric data also show that a MRSA episode entails an FEV_1 decline that is almost double that predicted for CF patients who can remain unaffected by MRSA.
http://tinyurl.com/f7ku8y3

Molecular fingerprinting of Mycobacterium abscessus strains in a cohort of paediatric Cystic Fibrosis patients. Journal of Clinical Microbiology. K. A. Harris, D. T. D. Kenna, C. Blauwendraat, J. C. Hartley, J. F. Turton, P. Aurora, and G. L. J. Dixon. Published ahead of print 7 March 2012 doi:10.1128/JCM.00155-12

The isolates from individual patients are indistinguishable and the data strongly suggests individual CF

TILLMAN *continued from page 32*

patients are persistently infected with one strain and also suggests that different CF patients can harbour the same strain.
http://tinyurl.com/7km2bkx

PRESS RELEASES

FDA Approves KALYDECO™ (Ivacaftor), the First Medicine to Treat the Underlying Cause Cystic Fibrosis

Vertex Pharmaceuticals Incorporated announced that the U.S. Food and Drug Administration (FDA) has approved KALYDECO™ (Ivacaftor), the first medicine to treat the underlying cause of cystic fibrosis (CF). KALYDECO is approved for people with CF ages 6 and older who have at least one copy of the G551D mutation in the cystic fibrosis transmembrane conductance regulator *(CFTR)* gene. Approximately 1,200 people in the United States, or 4 percent of those with CF, are believed to have this mutation. KALYDECO was granted approval in approximately three months, making it one of the fastest FDA approvals ever. The company has established a financial assistance and patient support program to help get KALYDECO to eligible patients for whom it is prescribed. KALYDECO is the first treatment to target the underlying cause of CF. KALYDECO will be taken as one 150-mg tablet twice daily (every 12 hours). KALYDECO should not be used with certain medicines, including the antibiotics rifampin and rifabutin; seizure medications (phenobarbital, carbamazepine, or phenytoin); and the herbal supplement St. John's Wort.

KALYDECO can cause serious side effects. High liver enzymes in the blood have occurred in patients taking KALYDECO. The most common side effects associated with KALYDECO include headache; upper respiratory tract infection (common cold) including sore throat, nasal or sinus congestion, and runny nose; stomach (abdominal) pain; diarrhea; rash; nausea; and dizziness.
http://tinyurl.com/18r

Synedgen Research Results Demonstrate New Therapy for Cystic Fibrosis Patients Chitosan Derivative Dissolves Biofilms, Reduces Mucus Viscosity and Enhances the Antibacterial Power of Tobramycin

Synedgen, Inc. announces new research results demonstrating that its proprietary chitosan derivative, SYN01, effectively dissolves biofilms, reduces mucus viscosity, and maintains broad antibiotic activity against Pseudomonas aeruginosa, a common cause of lung infection associated with cystic fibrosis.
http://tinyurl.com/6qscj5x

Long-term inhaled dry powder mannitol improves lung function in CF

Adding inhaled dry powder mannitol to standard therapy for cystic fibrosis produced sustained improvement in lung function for up to 52 weeks, according to a new study. Along with the treatment's efficacy and good safety profile, the convenience and ease of administration of mannitol treatment may improve adherence with therapy in these patients.
http://tinyurl.com/6v4pdzj

UK-based biotechnology company,

Continued on page 34

Information For People Who Travel On Airlines

In December of 2011, the Transportation Safety Administration (TSA) introduced a toll-free helpline that answers questions for fliers with disabilities and medical conditions. Disabled travelers may call ahead about screening policies, procedures, and what to expect at the security checkpoint. The purpose of the new helpline is to inform passengers with disabilities about certain policies before they fly so they may properly prepare for travel. The helpline may be helpful for people with cystic fibrosis who must travel with durable medical equipment, portable breathing machines, needles, liquid solutions (inhalant medications, insulin, etc.) and other medical equipment.

Travelers are encouraged to call at least 72 hours prior to a flight. People with CF and other medical conditions may call the "TSA Cares" toll-free number at: 1-855-787-2227. The helpline is available Monday through Friday, 9am – 9pm (Eastern Time) and is closed on all Federal holidays.

Individuals also may find information on traveling with special medical needs on the TSA Website at: http://www.tsa.gov/travelers/airtravel/disabilityandmedicalneeds/tsa_cares.shtm.

NovaBiotics' Lynovex has been granted orphan drug designation (ODD) in Europe (EU) by the Committee on Orphan Medicinal Products of the European Medicines Agency (EMA).

Lynovex is the company's novel dual mucolytic-antibacterial drug for the treatment of cystic fibrosis (CF). Lynovex (Cysteamine) is the first drug candidate with a novel dual mode of action which addresses the overproduction of mucous in airways and disrupts bacterial biofilms by attacking the bacteria that cause the recurrent infections associated with CF.
http://tinyurl.com/6pegfjp

Forest Labs Gets European Marketing Approval For Colobreathe Dry Powder Inhaler Forest Laboratories, Inc.said it has been granted European Medicines Agency approval to market Colobreathe dry powder colistimethate sodium for inhalation for treating cystic fibrosis patients aged 6 years and older with chronic lung infection caused by P. aeruginosa. Colobreathe is a capsule containing 1,662,500 IU of colistimethate sodium which is approximately equal to 125 mg. It is used with a Turbospin inhaler device which is a relatively small (10 cm long), portable medical inhalation device, and uses the patient's inspiratory flow to activate delivery of the dry powder into the lung. Each pack of Colobreathe will contain 56 capsules which is enough for 28 days treatment, and one Turbospin inhaler device, which is discarded at the end of the period.
http://www.rttnews.com

TRANSPLANT

Risk of Post Lung Transplant Renal Dysfunction in Adults with Cystic Fibrosis. Bradley S. Quon, MD, Nicole Mayer-Hamblett, PhD, Moira L. Aitken, MD,Christopher H. Goss, MD, MSc. Chest. January 2012 11-1926.

Renal dysfunction is common following lung transplant in the adult cystic fibrosis population. Increased age, female gender, cystic fibrosis–related diabetes requiring insulin, and pre-transplant renal impairment are significant risk factors.
http://tinyurl.com/7y4v4

Long-Term Impact of Liver Transplantation on Respiratory Function and Nutritional Status in Children and Adults with Cystic Fibrosis. J. K. Dowman, D. Watson, S. Loganathan, B. K. Gunson, J. Hodson, D. F. Mirza, J. Clarke, C. Lloyd, D. Honeybourne, J. L. Whitehouse, E. F. Nash, D. Kelly, I. van Mourik, P. N. Newsome. American Journal of Transplantation. Article first published online: 6 JAN 2012

DOI: 10.1111/j.1600-6143.2011.03904.x

For a select group of patients with cirrhosis due to cystic fibrosis liver disease, liver transplantation can stabilize long-term lung function and nutritional status and reduce the need for intravenous antibiotics.
http://tinyurl.com/88doofo

Ambulatory venovenous extracorporeal respiratory support as a bridge for cystic fibrosis patients to emergent lung transplantation. Don Hayes Jr, Jasleen Kukreja, Joseph D. Tobias, Hubert O. Ballard, Charles W. Ohopes. Journal of Cystic Fibrosis. Volume 11, Issue 1, Pages 40-45, January 2012

The authors describe the successful use of ambulatory single–venous Venovenous extracorporeal membrane oxygenation (VV ECMO) as a bridge to bilateral lung transplantation in 4 patients with end–stage lung disease due to cystic fibrosis who developed acute hypercapnic respiratory failure. The use of ambulatory single–venous VV ECMO was safe and effective in this small cohort of cystic fibrosis patients. ▲
http://tinyurl.com/715hdvm

Laura Tillman is 64 and has CF. She is a Director of USACFA and is the President. Her contact information is on page 2.

CF ROUNDTABLE SUBSCRIPTION FORM (Please Print Clearly)

PLEASE CHECK ONE: ☐ **NEW SUBSCRIPTION OR** ☐ **RENEWAL**

NAME _____ **PHONE (** **)** _____

ADDRESS _____

CITY _____ **STATE** _____ **ZIP+4** _____ **+** _____

E-mail address: _____

I am interested in CF Roundtable because I am a: CF ADULT _____ BIRTHDATE _____

OR I am a: Parent ____ Relative ____ Friend ____ Medical/Research Professional ____ Caregiver ____

A yearly donation of $15 for individuals, $25 for non-US addresses (US funds only) and $25 for institutions is recommended.
CF Roundtable is available free of charge to those who are unable to donate at this time.

- Annual donation . . . . . $ _____
- Additional donation to defray costs. . . . . $ _____
- Please send me the back issues I have listed on a separate sheet of paper.
  I am enclosing $4.00 per copy requested. . . . . $ _____
- Please send gift subscriptions to the names and addresses I have listed
  on a separate sheet of paper. I have enclosed $15 per subscription ordered. . . . . $ _____

TOTAL . . . . . $ _____

Please do not write in this space

SP 12

Make checks payable to USACFA and mail with this completed form to: USACFA, P.O. Box 151024, Alexandria, VA 22315-1024
Everyone must complete a subscription form annually to be included on our mailing list. Please check mailing label for renewal date.

HOW TO RENEW YOUR SUBSCRIPTION

Do you wonder when your *CF Roundtable* subscription is due for renewal? Have you wondered how to tell if it is time to renew? Look at your mailing label. Immediately after your name, there should be a date. That is your renewal date. (On the example, you can see that Kathy is due to renew her subscription in May 2012.) If there is no date or it says (TIME TO RENEW), your subscription is due for renewal.

KATHY RUSSELL 5/12
4646 NE DIVISION STREET
GRESHAM, OR 97030-4628

Please be sure to complete and return a form to us. You can help to keep our postage costs down by letting us know your current mailing address. To keep our records up to date, send us a notice when you move. (Any issue of the newsletter that is returned to us costs us about two-and-a-half times the first-class postage rate for that piece. Currently that runs about $3.73 per returned copy.)

Thank you for helping us with this.

CF Living

CF Living

Check out the new *CF Living!* As many of you may know, *CF Living* is an educational program that offers information and support for those living with or caring for someone with cystic fibrosis. Genentech is proud to offer you this updated form of support, and we encourage you to check out all the new features on the site that are now available. The new *CF Living* is designed to help you work more closely with your Care Team, learn about treatment options, and provide interactive educational resources so you stay informed. Enroll today at: https://www.cfliving.com/ to begin taking part in this informative program!

REMINDERS

- Please notify us immediately of any address changes. Returned mail wastes money and delays mailings.
- To keep our mailing list current, we require the completion of a subscription form every year, even if you are unable to make a donation. Your address label indicates when it is time to renew. Subscriptions stop automatically if not renewed regularly.
- We would like to act as a referral source for active adult support groups. Please send us your group name, leader's name and phone number, number and age range of your members and geographical area covered, and we will add you to our referral list.
- Please let us know of the major occurrences in your life (*e.g., marriages, births, completion of educational degrees or training, career advancement, transplants, anniversaries, birthdays*) and we will print your information in **Milestones**.
- Share your ideas for **Focus Topics**, feature articles or any suggestions for improvements you may have to help make *CF Roundtable* more relevant and interesting to you.
- You can reach **USACFA** and ***CF Roundtable*** at anytime by phone **(248) 349-4553**. You may email us at **cfroundtable@usacfa.org**
- Send your questions of a general nature regarding legal issues that relate to CF to our legal advisor: **Beth Sufian, Esq., 712 Main, Suite 2130, Houston, Texas 77005. Email: cflegal@cff.org**.
- You may subscribe at cfroundtable@usacfa.org

Published by the United States Adult Cystic Fibrosis Association, Inc.
CF Roundtable is printed on recycled paper.

IMPORTANT RESOURCES

Partnership for Prescription Assistance: Phone: 1-888-477-2669 http://www.pparx.org/prescription_assistance_programs
The Partnership for Prescription Assistance brings together America's pharmaceutical companies, doctors, other health care providers, patient advocacy organizations and community groups to help qualifying patients without prescription drug coverage get free or low-cost medicines through the public or private program that's right for them.

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

Transplant Recipients International Organization, Inc. (TRIO): Phone: 1-800-TRIO-386 http://www.trioweb.org/index.shtml
An independent, nonprofit, international organization committed to improving the quality of life of transplant recipients and their families and the families of organ and tissue donors. For information, write to: TRIO, 2100 M Street NW, #170-353, Washington, DC 20037-1233 or e-mail them at: info@trioweb.org

American Organ Transplant Association (AOTA): Phone: 1-713-344-2402 http://aotaonline.org/default.aspx
Helps defray out-of-pocket travel expenses for transplant recipients. Helps to set up trust funds. For more information, write to: AOTA, 21175 Tomball Parkway #194, Houston, TX 77070-1655

ADA: To learn how the American with Disabilities Act (ADA) applies to you, contact the Disability Rights Education and Defense Fund (DREDF): Phone: 1-800-348-4232 http://www.dredf.org/