

## CF And Insomnia ... Are You Down With Herbal Medications?

By Aaron Huwe, Pharm.D., Director of Clinical Development, A-Med Specialty Pharmacy

In a previous issue of *CF Roundtable*, the Focus topic centered on sleep in the CF community. Being a pharmacist, I wanted to address the use of herbals, since many CF patients question if herbal medications are appropriate for them. First and foremost, people living with CF should keep their health care providers informed if they have trouble sleeping (or other lifestyle issues) and what medications they are taking, whether prescription or nonprescription. This will assist your physicians and pharmacists so that they can make informed decisions to fit your lifestyle and better your health. Secondly, there is limited research into the utility of herbal medications in the CF community and the current CF guidelines do not address the use of herbal medications.

Some patients are unaware of

many of the medications they take and this medication familiarity declines when we venture in the realm of nonprescription medications. In the United States, nonprescription medications can be defined as herbal, dietary supplements, alternative or over-the-counter (OTC) medications. What patients often don't know about nonprescription medications can hurt them. One fact that all patients and health care providers should know is that nonprescription medications are not regulated by the U.S. Food and Drug Administration (FDA). (The FDA is the governing body that oversees approval of prescription medications and exists to ensure that medications are both safe and effective.) As a result, nonprescription medications have not been proven to be safe nor effective since they are regulated to

the same extent as food and not subject to the FDA approval process.

This does not mean that all nonprescription drugs are dangerous; instead, it means that one must proceed with caution and inform their health care providers if nonprescription medications are taken. The concern with non-prescription medications is that patients perceive them as safe/benign and do not disclose to their doctor what they are taking. As with prescription medications, nonprescription drugs can also have potential drug interactions and change how a patient responds to prescription medications. Drug interactions are of concern for patients with chronic illnesses and complicated medication regimens, such as people living with cystic fibrosis (CF). One additional concern is that there

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# EDITOR'S NOTES

Hello Readers, we have some exciting news! *CF Roundtable* is now available online. Our website: [www.cfroundtable.com](http://www.cfroundtable.com) has been redesigned to be more user-friendly. You will be able to register online using Paypal to pay for annual subscriptions, download a PDF of the newest *CF Roundtable* (available 3 weeks prior to the printed version) or opt to receive both printed and online versions. In an effort to reach out to our audience, some of our Directors will be blogging, using Twitter and managing a Facebook page. Look for these announcements on Cystic-L and please follow us in our foray into social media.

For this issue, our Focus topic is Hobbies and Pleasure Activities. **Jeanie Hanley**, inspired by "Roots", the mini-series from the '70s, found her favorite hobby to be genealogy. Plus, she can do it while doing her treatments at the computer. **Brian Weinstein** feels that spending time working-out or riding his motorcycle, does a mind and body good. **Bracha Witonsky** returns to her first love, singing, and finds that through voice exercises she improved her PFTs. **April Thompson** writes about joining a roller derby team and her exhilaration at making the all-star-traveling team. **Nicole Matthews'** hobbies are volunteering as part of the fire department, ice-skating with handicapped children, dirt biking and camping. **Kathy Russell** carries this theme into her *Speeding Past 50* column. She finds that since she retired, she has so many hobbies and things she loves to do, she has never been bored. Likewise, **Julie Desch** writes in her *Wellness* column about the importance of being "in the zone" or flow. This is when someone is focused and involved in the success of an activity, just like a hobby or athletic achievement.

In *Ask the Attorney*, **Beth Sufian** discusses the guidelines for the new SSA benefits that will help anyone who may consider applying for disability benefits. In *Spirit Medicine*, **Isa Stenzel Byrnes** examines guilt and how it, if left unanalyzed, can damage our spirits. In *A Deep Breath In*, **Debbie Ajini** discusses the "3-Foot Rule" with regard to CF Patients and the contrast of how it used to be in her youth. In *Voices from the Roundtable*, we hear from **Jennifer Hale** and **Emily Heise**, who share their stories about their lives with CF. **Laura Tillman** updates us on what is new in CF research in *Information from the Internet*. In *Poetry Corner*, **Nicole Matthews** shares her poem, "She Fights Everyday".

Please check out CFRI's Annual CF Family and Education Conference as well as the CF Teen and Adult Retreat information on page 30. And for those considering pursuing higher education, see page 33 for CFCareForward Scholarships offered by Abbott.

Even though we are going "high-tech" with a new website and new subscription options, our goal is to produce the best newsletter we can. Through the use of social media to elicit our readers' comments, feedback, interests, and concerns, we plan to produce a newsletter that involves everyone's interests.

PS We still will accept subscriptions and donations via our subscription form on page 35.

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



## Mailbox

I'd like to report the anniversary of my bilateral lung transplant, 18 years on February 10, 2011. Maybe it will inspire some people who are on the fence to consider a transplant. Thanks for your great newsletter.

*Paul Albert*  
Catasauqua, PA

Thank you for your publication. We both look forward to its arrival .

*Joanne & Adam Brockmiller*  
Union, MO

Thanks for the great adult *CF Roundtable*. I always enjoy reading it and it is very informative. My daughter, Danelle, has CF and is 44 yrs old. She had a bilateral lung transplant 11 years ago. She is married, works full time, and is a blessing to all of us. Thank you for your efforts.

*Marie Roulier*  
Storrs Mansfield, CT

Great newsletters!

*Sylvie VanGeel*  
London, Ontario, Canada

I am the father of Jon Jantomaso of Seminole, Florida, who had a very successful double-lung transplant on April 11, 2010, at Mayo Clinic, Jacksonville, FL. Jon is 44 years old and married with three beautiful adopted girls. As with so many CF patients, he has a miracle story jam-packed with accomplishments. He was diagnosed with CF at 6 weeks of age. I recently wrote a paper on Jon's journey to transplant. I wrote it to encourage CF patients of every age and their parents and/or caregivers. I've been Jon's caregiver pre- and post-transplant, and the joys of it all were immeasurable. Thank you all for all your efforts and heartfelt time in CF.

*Pat Jantomaso*  
Treasure Island, FL

Keep up the good work. Thank you.

*Stephanie Rath*  
Brownsburg, IN

## 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](mailto:cfroundtable@usacfa.org)

**Spring (current) 2011: Hobbies And Pleasure Activities.**

**Summer (August) 2011: If Only I Had Known Then What I Know Now.** (Submissions due June 15, 2011.) Do you find that there are things that you have learned along the way that could have made your life easier? Are there tips that you can share with our readers? What are some of the "must know" facts about living with CF, or things that you wish you had known when you were younger?

**Autumn (November) 2011: CF, It's Not Just For Children.** (Submissions due September 15, 2011.) The face of CF has changed over the years. Now many people live into their 30s, 40s, 50s and beyond. Tell us about dealing with the problems of aging when you have what many consider to be a "pediatric" disease. Tell us how CF is different for you, now that you are an adult.

**Winter (February) 2012: Our Pets and How They Affect Our Lives.** (Submissions due December 15, 2011.)



# ASK THE ATTORNEY

## New Guidelines for SSA Disability

By Beth Sufian, Esq.

**B**ecause I receive so many questions about Social Security Administration (SSA) benefits, many columns have been devoted to issues related to SSA benefits. Most people with CF receive some type of SSA benefits, at some point in their lives. This column will focus on new guidelines issued by the Social Security Administration regarding criteria SSA can consider when reviewing an application from a person with CF.

Nothing in this column is meant to be legal advice about

your specific situation or is meant to suggest you may or may not be eligible for Social Security benefits. If you have additional questions please contact the CF Legal Information Hotline at 1-800-622-0385. The Hotline provides free and confidential legal information to people with CF, their families and their CF Center care teams. The Hotline is proudly sponsored through a grant from the CF Foundation. The Hotline can also be reached by e-mail at [CFlegal@cff.org](mailto:CFlegal@cff.org).

Eligibility criteria for SSA benefit programs that relate to disability are often difficult to understand. However, obtaining SSA benefits is the only way for some people with CF to receive health insurance coverage and monthly benefits that help them with living expenses when the person is not able to work due to health issues. It is important to understand the eligibility criteria. It will be very difficult for people to obtain SSA benefits if they do not know what evidence is needed to show SSA that they meet the eligibility criteria. Just being in need of health insurance coverage does not make a person eligible for SSA benefits. Just having a diagnosis of CF does not make a person eligible for SSA benefits. It is important for everyone with CF to understand the eligibility criteria for benefits.

This column will discuss medical criteria and briefly mention one of the non-medical criteria. There are many non-medical criteria a person must meet to be eligible for SSI or SSDI benefits. A future column will discuss those criteria.

Basically there are four medical criteria described in SSA regulations that relate to the pulmonary complications caused by CF. While there are SSA medical criteria for a person with digestive issues or liver disease, the majority of people with CF qualify for benefits



**BETH SUFIAN**

based on the pulmonary criteria.

A person with CF must meet one of the criteria in order to meet the medical requirements for benefits or must show his condition is as severe as one of the listed criteria. A summary of the criteria follows. This is only a summary. For the exact criteria contact the CF Legal Information Hotline or go to [www.ssa.gov](http://www.ssa.gov).

1. Low pulmonary function (FEV<sub>1</sub> of approximately 50% - the number depends on height) for the past year; or

2. Six physician interventions for pulmonary exacerbations in the

past year; or

3. Three hospitalizations in the past year; or

4. Persistent pulmonary infection requiring intravenous or nebulized antimicrobial therapy once every six months in the past year.

5. For children, an additional criterion is proof of significant growth impairment in the past year.

In the past year Social Security has issued new national guidance to be used by Social Security representatives who review SSA benefit applications from people with CF. The SSA guidance is a policy clarification for the SSA employees handling claims in local offices across the country. The new national guidance is significant because it explains how Social Security representatives may use additional reasons to find that a person with CF is eligible for benefits.

Under the new guidance Social Security must take into consideration certain medical evidence when deciding if an adult applicant is unable to engage in full time work or when deciding if a child is functionally limited due to CF. SSA must consider the evidence, but having evidence of certain medical issues does not guarantee approval of an application for SSA benefits.

SSA will now consider four different types of medical evidence in addition to the criteria listed above.

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*Just having a diagnosis of CF does not make a person eligible for SSA benefits. It is important for everyone with CF to understand the eligibility criteria for benefits.*

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First, evidence the applicant has issues of fatigue and sustainability (the ability to sustain work activity). Evidence that a person with CF has to take unscheduled breaks to rest during the work day or to perform medical treatments should be considered. Excessive absences due to sickness, clinic visits or hospitalizations should be considered. In addition, limitations with standing, walking or engaging in the physical activity that is necessary for full time work should also be considered when evaluating an application for SSA benefits by persons with CF. Of course SSA will know that a person with CF has these problems only if the problems are noted in the person's medical records and discussed in the application for benefits. It is important to make sure the CF physician documents issues dealing with fatigue and sustainability in the clinic visit notes.

The second category of evidence SSA should consider is the effect of medical treatments on the applicant's ability to perform full time work or the ability to function as a child. Issues such as time to perform nebulized medication treatments or home IV treatments should be considered. The time it takes to perform medical treatments related to other medical issues such as diabetes, digestive issues, liver issues, sinus issues or arthritis can also be considered. This information needs to be documented in the CF clinic visit notes and in the application for benefits.

For example, Albuterol - 15 minutes, Pulmozyme - 15 minutes,

Hypertonic Saline - 45 minutes, TOBI - 45 minutes, Vest or other airway clearance technique - 30 minutes. Make sure medical records indicate if such treatments are performed once or twice a day. Include the amount of time it takes to clean all nebulizers. If a person is unsure how much time it takes to do all treatments and clean all equipment he should take one day and perform all treatments (turning the machine off if coughing starts) and how long it takes to clean all equipment. Most people are surprised when they see how much time it actually takes to do a full set of treatments and clean all equipment afterward.

The third type of evidence SSA should consider is environmental restriction. Evidence that certain environmental conditions in a work environment will exacerbate CF medical complications is important. For example, if extreme heat or extreme cold would affect a person this should be noted in the clinic visit notes prior to an application for benefits being filed. Any other environmental restrictions should be noted and discussed in the application for SSA benefits.

Lastly, SSA should consider the combined effects of multiple conditions on the applicant. For example, if a person has digestive, sinus and pulmonary issues, evidence of the effect of all conditions on the person should be discussed in clinic visit notes and the application for benefits. SSA should consider whether the combination of medical conditions rises to the level of one of the

listed medical criteria.

The SSA National Guidance is new and applicants should not expect SSA to magically figure out how the person may qualify for benefits based on the new guidance. The applicant must present medical proof that one or more of the issues set out in the new guidance impacts the applicant's ability to work full time. If the applicant is a child, the applicant should discuss how the issues make the child functionally limited and, therefore, eligible for benefits.

In addition to meeting the medical eligibility criteria an adult cannot be engaged in full time work and cannot make more than \$1000 from part time work while applying for Social Security Disability Insurance benefits. If a person is working full time he will not be eligible for benefits even if he meets the SSA medical criteria or meets one of the criteria discussed in the new guidance.

Applying for SSA benefits can be confusing and complicated. It is much better to understand the eligibility criteria before a person applies for benefits than to realize that a person did not submit proper evidence to show that she meets the medical criteria and thus is eligible for benefits. The initial application is very important. Mistakes made on the initial application are difficult to fix during an appeal if the initial application is denied. People with CF can contact the CF Legal Information Hotline to receive information on the SSA eligibility criteria at 1-800-622-0385. All calls to the Hotline are free and confidential. ▲

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*Beth is 44 and has CF. She is a Director of USACFA and is the Secretary. Her contact information is on page 2. She is an attorney who specializes in disability claims. You may send CF-related questions of a legal nature to: [bsufian@usacfa.org](mailto:bsufian@usacfa.org).*



# SPIRIT MEDICINE

## Guilt: Committing Shouldicide

By Isabel Stenzel Byrnes

Last January, I flew to Las Vegas to give a talk. I took the opportunity to visit the gravesite of my best friend, Karen, who lived there and died of cystic fibrosis (CF) 21 years ago. When I approached her grave, I noticed two additional graves, side by side. One was for her sister, Katie, and one was for her brother, Kevin. They all had CF and now they all were gone.

I stood looking over these graves, remembering our last interactions. Karen was so sick, but I couldn't see it, therefore dismissing her subtle cries for support. Katie lost her hearing from Amikacin, and I dreaded her hour-long calls using a TDD telephone operator. Kevin had last sent me an incoherent email, and I never really responded.

What did all these thoughts bring up? Guilt. Guilt over what should've happened, what I should've said or done to authentically 'be there' for them. If only I did more for them, perhaps their short lives would have been more understood or enriched in a small way. And to top it off, I've lived 20 years longer than Karen. I don't understand why.

Therefore, guilt is the subject for this Spirit Medicine. After decades of conversations with friends with CF, I've noticed that guilt subtly permeates this community.

With the exception of psychopaths, everyone feels guilt. This is a heavy duty emotion of moral judgment and deserves a thorough examination. I could write volumes on guilt but, for now, I'll briefly examine guilt

in those touched by CF.

What does guilt have to do with spirituality? Guilt becomes a weight that we carry around. If not worked through, guilt can lead to depression, isolation, and despair, all of which can damage our spirits. Likewise, imposing guilt on others is a way to control and manipulate them, thus dampening the spirits of other people.

Also, our guilt can be alleviated

and induced by our spiritual traditions. Letting go of guilt through repentance or forgiveness can offer tremendous emancipation. Yet, our own spiritual beliefs can influence what guilt means. Buddhism focuses on the detachment from emotions, including guilt. Confucianism, the inspiration in Asian cultures, says, "Always conduct yourself with a sense of shame." Being half Japanese, I

know all about shame (a term used for guilt and humility together). Judaism and Islam say that guilt comes from specific behavior, while Christianity says guilt is based on sinful thoughts and feelings. Some faiths can impose guilt by threat, if one does not abide by the rules of that religion. My Jewish

and Catholic friends often joke, "If I'm breathing, I'm guilty."

Though guilt involves some regret, remorse, shame and sense of "I should have," I'll focus on two types of guilt. First, we feel guilty when we have control over something and do not act or act inappropriately. (I'm not going to address guilt related to crime or the Ten Commandments. That's for another volume!) Second, and more importantly, we feel guilty about things over which we have no sense of control.

When we have control, our choices are often guided by how much guilt we want to tolerate. If I'm paying for a gym membership, and don't go for a week, I feel guilty that I'm wasting money. So I go. Similarly, in my twenties, I struggled to balance life

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*Guilt becomes a weight that we carry around. If not worked through, guilt can lead to depression, isolation, and despair, all of which can damage our spirits.*

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ISA STENZEL BYRNES

demands with CF healthcare. I'd tell myself all the things I should be doing: more therapy, exercise, eat more, rest more. This hovering sense of "should" would wear on me, though I tried to take Stuart Smalley's self-help advice, "Stop shoulding all over yourself." But, in actuality, this sense of 'should' forced me to take care of myself.

Guilt also serves a positive purpose in my relationships. I often don't feel like doing anything with friends, as it's safer to be a hermit. But, my sense of obligation to them – the guilt I'd feel if I let them down – has gently compelled me to spend time with them and stay engaged. Then, I usually end up having a great time. So, a little guilt is good for everyone; it keeps us connected (and nice) to each other. Guilt is our conscience speaking. I mean, when was the last time guilt made you call your mother?!

Then there's the mysterious guilt that plagues us over things for which we have no control. Just by the fact that we don't have control makes us play the mind game and pretend we have some control – using guilt. When I had end-stage CF, I despaired over what else I should be doing to get better; but really, there was nothing more I could do. I felt like I was doing something wrong for being so sick, and tormenting myself with "emotional shouldicide." Truthfully, CF was so powerful and I had no control. The guilt was not justified.

Similarly, after waking up from an eleventh hour lung transplant, I felt guilty that someone else died to save me. I had to work through that guilt by understanding that two things happened: my donor died, and I received a lung transplant. I didn't cause his death. His accident and death had nothing to do with my desperate need for lungs. It was just through Grace that we were connected.

Though I'm not a parent, parenting seems to impose guilt over some

things that are uncontrollable. I've observed that some CF adults who have children spoil them rotten. I wonder if guilt is involved – guilt over the attention their health needs take away from parenting. Parents of CF children might experience guilt over not being able to take away their child's suffering. My mother said in an interview, "Every hospitalization my daughters experienced I felt like I did something wrong." Another CF mother said she feels guilty that her toddler screams and cries during treatments, so "sometimes I just let treatments slide." This causes more guilt.

The hallmark of parental guilt is that CF is genetic. One Japanese father of a CF infant asked me, "Are you angry at your parents for giving you CF?" I replied, "Absolutely not." I explained how grateful I was for a wonderful life, even with CF. He then said, "Oh good. Now I can look in the eyes of my son."

Guilt is often illuminated at the end of life. I truly felt guilty when I was dying, because of the pain my death would cause my parents and partner. Though I don't have the authority to write for parents, when a person dies with CF, grieving parents are most vulnerable to feeling guilty over what could've and should've been done. Grief and guilt go hand in hand. Guilt is a desperate way to gain control over an overwhelming situation. Survival guilt is an adaptive response to help sustain emotional engagement with our loved ones who are gone. It may be painful to get rid of that guilt, as a final letting go. What I've witnessed is that only through years of thoughtful reflection over the loss — examining what is one's responsibility or not, and finding healthier ways to connect to the deceased — does the survivor guilt start to dissipate.

So, how do we deal with guilt? To leave guilt alone is self-flagellation. One must feel worthy of living free of

this oppressive feeling. We cannot shove guilt under the rug and hope it goes away. It must be dealt with or serious problems can arise. Rev. Dr. Martin Luther King said, "Sometimes having a sense of guilt can lead to repentance or a desire to change. In some, however, it can cause someone to indulge in more of the very thing that one has a sense of guilt about, as if to compensate and drown that sense of guilt." I wonder if this means that if someone with CF skips their treatments, they could be feeling guilty, and that guilt might be fostering continued non-adherence. I'm not sure if this resonates with anyone.

To manage guilt, one must first recognize and acknowledge the feeling. An admission of guilt can be followed by a choice to act on the guilt; that is, to do something about it. For example, I've always felt bad that my sister had more severe CF than I did. But I harnessed that guilt by trying to help her out as much as I could.

Sometimes one cannot take practical action to alleviate guilt. Instead, one can reappraise the situation and make internal choices to reconcile the guilt. Regarding my twin's more severe CF, my guilt manifested by telling her what to do, over and over again, in an attempt to control the uncontrollable situation. This would make her feel bad and I'd feel worse. And finally there came a point when I'd see it and decide to stop. There is a time to let guilt go. My sister's disease is what it is and mine is what mine is. Buddha said, "After crossing a river on a raft, abandon it at the other shore. Do not lug the raft into the forest where you no longer need it."

A key element to dealing with guilt is accepting responsibility. If there's no responsibility to be had, there is a need to acknowledge that. When I feel guilty over the deaths of Karen, Katie and Kevin, I must realize

*Continued on page 11*



# SPEEDING PAST 50...

## What Boredom?

By Kathy Russell

When I was paid for my time, I got days off and had some time to do whatever I wanted to do. Since I stopped getting paid for my time, I have had almost no “leisure” time. I remember that when I retired, my coworkers told me that I would be “bored” within a couple of months of stopping work. Not true! There always is something that needs doing. Now, that doesn’t mean that I get it all done, it means only that there always is something to do.

When I decide to do something that is just for fun, I like to cook or bake, make jewelry, sew, make Raggedy Ann and Andy dolls, do crewel embroidery or cross-stitch, do crossword puzzles, do jigsaw puzzles and, perhaps most of all, read. I get large print books from our local library and have a fine time with light and airy mysteries. I don’t want to read anything that is full of “darkness” or people who are mean. The books that I like are filled with quirky characters whom I might enjoy having in for coffee – if I drank coffee.

I find that reading light “stuff” can help me to get away from the everyday chores and activities that can wear me down. I can get so lost in a book that I forget about time. It always has been that way for me. When I was young, the librarian knew the kinds of books that I preferred and she would make sure that they were available to me. Because of her, I traveled the world in books while I was very young. I believe that fueled my interest in travel.

When Paul (my husband) and I were young, we traveled a lot. His folks lived in NYC and we lived in

Oregon. Frequently, we went home (to NYC) for a long weekend. (Paul worked for a large airline and we had travel benefits that allowed us to travel at very low cost.) We also went to other parts of the USA and to other countries. In the first 20 years of our marriage, I flew about 600,000 miles. (I know... “Boy, were my arms tired!”)

As we got older, we traveled less. Partly it was because of all of the medical equipment that I need every day and partly it was just that, as we aged, travel was more effort and less fun. We did take a trip to Pennsylvania recently and I did enjoy it. My Inogen One G-2 portable oxygen concentra-

tor worked great and all the people with the TSA seemed to be much nicer and less harried than the previous times we had traveled. Maybe we will consider flying places again.

I haven’t done as much with jewelry making, embroidery or sewing as I would like to, for the past few years, because I have a little problem with my eyesight. It is difficult for me to do anything that takes fine focus. I hope that as I age my eyesight may improve, since I am very nearsighted and most people become a little more farsighted with age. We’ll see. At least I can hope for improvement.

Earlier, I mentioned Raggedy Ann and Andy dolls. I have made a few of them for special people. I love to see the fabric come to life as I create clothes for these little characters. Putting a heart on each one is special, too. The best part is when I create their faces. They are so happy and unthreatening. They are just my kind of critters.

I love doing jigsaw puzzles. I prefer designs that have water and blue skies, but I do most any happy country scene. There are a few types of puzzles that I really like. Three artists whom I like are Heronim, Charles Wysocki and Jane Wooster Scott. All three of them create scenes that I enjoy putting together. I like puzzles that are at least 1000 pieces. They will take me a few hours to complete and let me forget all that is unpleasant in the world.

I used to spend many hours doing photography. I really loved taking photos, especially portraits. I invested in good camera equipment and special lenses. I took some portraits that

*I find that reading light “stuff” can help me to get away from the everyday chores and activities that can wear me down.*



KATHY RUSSELL

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turned out to be the best photos ever done of some people. I really worked at getting the personality of the subjects and enjoyed every minute of it.

When Paul was still working, he was on the afternoon shift. After he left for work and I got the kitchen cleaned up from lunch, I would go to my office and start working on photos. Many times, I would get so engrossed in what I was doing that, before I knew it, Paul was driving up the driveway. I had spent eight hours totally enrapt in what I was doing and hadn't even noticed the passing of time. Now that is what I call a real hobby. Even though I don't take many photos now, I still enjoy working with photos and trying to make each one the best that I can.

Another joy in my life has been my mother's piano. Mother was a pianist and, when she was a little girl,

that fills some time and brings us great joy. That one is growing plants. I have a garden window above the kitchen sink. It is full of African violets, begonias, Zygo cactus, hoyas and chandelier aloe plants. For some reason I am able to propagate all of these with little effort. (One violet plant is now 12 new plants!) I also have several more cactus plants, a gardenia and an areca palm in the living room, near my favorite chair. Even if I feel rotten, I can look at these plants and feel better. When the Zygos bloom, they resemble orchids. The blossoms are quite spectacular. I feel that they are a special gift for us.

I suppose that I should include writing among my hobbies. At least, I should include writing in how I spend my time. Currently, as well as writing this column, I write for another newsletter and am doing the publicity

Environmental Design" presentations for my city. Going into the homes of residents of my city gave me a great way to get to know many people and to help them make their homes safer. I worked through the police department and found our police officers to be a great bunch of citizens.

For the past 21 years, the US Adult CF Association (USACFA) and *CF Roundtable* have been my primary activity. I helped to establish our organization and became the first Treasurer of USACFA. Since that time I have remained on the Board of Directors and have served in various capacities. Besides writing this column, I help with editing and proofing the newsletter. Believe me these jobs keep me plenty busy.

You may have noticed that most of my hobbies are basically sedentary. Since my energy is limited, I find that doing things that don't take much energy works best for me. My days of running up and down stairs (or even walking up and down stairs), going from morning until night nonstop and always being able to do whatever I need to are gone. I am able to do my treatments, fix meals, do laundry, do a little shopping and that's about it. I am not complaining. I am delighted to be able to do all that I can and I am grateful that Paul does everything else. I'd be lost without his help.

My days are full and fulfilling. Many days I manage to get in a nap. Sometimes it is only 20 minutes or so. Other days, it may be a couple of hours. I listen to what my body says and go with that. I hope that by managing my energy and husbanding my strength, I will be able to keep on doing the things that I enjoy. However, I still am waiting for the time that I feel bored.

Stay healthy and happy. ▲

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*Kathy is 67 and has CF. She is a Director of USACFA. Her contact information is on page 2.*

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## *Since I stopped getting paid for my time, I have had almost no "leisure" time.*

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her father bought her a Steinway upright piano. That piano is sitting in our home and I love playing it. I never would play for anyone but Paul and myself, but I do enjoy it. For a piano that was built in 1873, it still has great tone. It is sometimes a little slow to respond, but it is 138 years old! When I play it, it brings back many wonderful memories of Mother playing it for me. The sounds are so familiar and comforting. The rosewood of the case is lovely and I feel that it is a beautiful piece of art. Someday, when I feel that I have some money that has no better purpose (does that time ever happen?) I will have it refurbished. Until then, I will enjoy every note it plays, even if some do stick a little.

I haven't mentioned one hobby

for an upcoming convention. For a person who never really enjoyed writing, I find that I do a lot of it. I am getting used to it and am even getting to like it. As far as the publicity goes, it is a challenge to figure out new ways to say the same thing without being redundant. This column is more fun because I can write it as if I were talking with a friend. After all, that is how I think of our readers. These friendships are very important to me.

When I write of things that fill my time, I can't forget volunteer work. I have written in the past of being a volunteer since I was a little child. Volunteering is so rewarding. I have volunteered for my city as well as for nonprofit and other organizations. I used to give "Neighborhood Watch" and "Crime Prevention Through

is no standardization for nonprescription preparations and they may contain varying amounts of the active ingredient, thereby eliciting differing effects. As a result, special attention must be made when taking nonprescription medications to ensure that one is taking the same dose/strength of the medication. With that said, nonprescription medications have a place in therapy for many patients, so long as they are approached in a similar fashion as we do with prescription medications. For the sake of our discussion, we will focus on the herbal perspective to nonprescription medications.

Insomnia or the consistent inability to sleep is a frequent problem for patients with chronic diseases; particularly those living with CF. Insomnia can result from stress, pain, and even be caused by some medications. Sleep is an important restorative function of the body and is important particularly for those with chronic illnesses. As a result, many patients opt to take medications to help them sleep. While there are a number of prescription medications available to facilitate sleep, some patients are reluctant to take them due to potential side-effects or the addition of another medication to an already complicated regimen. In addition to prescription medications, there are a number of different herbal or alternative medicines to help with sleep. We will discuss two of the most common: Melatonin and Valerian.

Melatonin is a naturally occurring hormone found in the human body that is involved in the sleep-wake cycle. Melatonin has been available as an over-the-counter dietary supplement since the 1990s and, like other herbal medications, has not been formally evaluated by the FDA regulatory process. Melatonin has shown potential in treating ADHD, seasonal affective disorder, and headaches in addition to its benefits in regulating the sleep cycle. Although it is uncertain how melatonin interacts with the immune system,

some studies have hinted that melatonin may have promise in infectious disease processes such as viral and bacterial infections, even cancer. As such, the impact specifically on CF has not been studied and melatonin should be used primarily to promote sleep.

To promote sleep, melatonin is available in tablet formulation from a number of different manufacturers. The recommended dose for adults is 0.3mg - 3 mg, 30 minutes prior to sleep. Melatonin, like many dietary supplements, has not been studied in children and as a result, current labeling for melatonin-containing products does not provide recommendations for children. Melatonin may cause the following side-effects: fatigue, dizziness, headache, irritability, drowsiness, and sleepiness. Some experts urge that melatonin should not be used in some patients, such as those with depression, autoimmune diseases or serious illnesses. Melatonin can have potential drug interactions with the following medications: antidepressants, benzodiazepines (for anxiety), calcium channel blockers (for blood pressure), opioid analgesics (for pain), diabetes and sleep medications. It is advisable to consult with your doctor or pharmacist before starting melatonin or other herbal therapy.

Valerian is an herb that has been used since the mid-1800s to treat insomnia and relieve anxiety, and was provided to many veterans returning from World War II. It remains uncertain how valerian works in the body, but is likely implicated in regulation of certain neurotransmitters. Valerian is available in a number of different formulations: tea, liquid and capsule, with the capsule modality preferred. Dosing of valerian ranges from 300mg - 900 mg, taken 30 minutes to 2 hours before bedtime. It is important to note that it can take 2-3 weeks before a patient will see the potential benefits of valerian and use should be limited to 3 months at a time. As with melatonin, there are no recommendations for use in the pediatric population and should be avoided unless

under physician recommendation/supervision. Potential side effects to valerian include indigestion, headache, palpitations and dizziness. Unlike other prescription or nonprescription sleep medications, valerian is not associated with addiction or grogginess (the hangover effect). In terms of drug interactions, valerian should be avoided with several medications, including those that have an effect on the central nervous system such as antidepressants, opiate analgesics (pain medications), benzodiazepines (anxiety medications) or other sleep medications.

To summarize, here are some important takeaways:

People living with cystic fibrosis should discuss the potential benefits and risks of nonprescription medications with their CF care centers. This will help them take better care of you by limiting potential drug interactions and having a better understanding of what medications you are taking.

Limited research has been done to look at the utility of herbal medications in the CF community and the current CF guidelines do not address the use of herbal medications.

There are no current recommendations for herbals and nonprescription drugs in the pediatric population. As such, one should first consult with the CF care team to weigh the risks and benefits of herbal therapy.

Melatonin and valerian can be useful to help maintain better sleep patterns. Like prescription medications, even nonprescription drugs come with side effects and can pose significant drug interactions with medications you already are taking.

Do your own research and read the blogs of other CF patients to see what works for them and, on the contrary, what does not work. ▲

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*Aaron Huwe is a Doctor of Pharmacy and the Director of Clinical Development at A-Med Specialty Pharmacy in Huntington Beach, CA. You may contact him at: [ahuwe@a-med.com](mailto:ahuwe@a-med.com)*

# She Fights Everyday

By Nicole Matthews

The doctors told me the news, I wanted to cry,  
I prayed in the pews,  
Hoping that she won't die.

I watch her grow day by day, The choices she makes,  
Only wishing that she'll stay.

I tell her to do her treatments,  
She just ignores me even more.  
She sits there coughing up secretions, As I shut her bedroom door.

Without a thought,  
She has a heart of gold, She cares for everyone, Both young and old.

I know she gets down in the dumps, But one needs to understand,  
She conquers some pretty big humps, Some more than grown men.

I worry everyday,  
That it may just be her last. But today she is here,  
And having a blast.

Three years old she called it, Sixty-Five roses,  
Now twenty-one calling it, cystic fibrosis.

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*Nicole is 22 and has CF. She lives in Orchard Park, NY.*

**BYRNES** continued from page 7

I have no responsibility for my friends' deaths. I can only feel compassion for them, together with compassion for myself and the helplessness I have for their situation.

Also, I have a guilt mantra. When facing guilt, three words give me solace: "Guilt implies intent." If I didn't intend to cause harm or offense to myself or others, then I need not feel guilty. I can feel sad or bad, but the thing for which I feel guilt is not my fault. Easier said than done! This is complex stuff. Pervasive guilt without intentional wrongdoing deserves deep investigation through psychotherapy.

It can also be helpful to relinquish control over one's guilt to a higher power. Most religions offer prescribed ways to deal with guilt: by feeling bad, punishment, reconciling with the person we offended, confession and repentance, abstaining from doing wrong, or promising not to repeat the wrongdoing. A spiritual conversation about one's guilt can help to find forgiveness for oneself. Prayerful meditation requires discipline and outlet; but this is true spiritual medicine. Spiritual introspection reminds us to accept our humanness, our fallibility, our normality. Relief of guilt is like the clouds parting in the sky...everything looks clearer.

No one deserves to wallow in guilt, especially us. People touched by CF have enough suffering! If you feel guilty over something, I invite you to embark on an investigation of that guilt. No pressure, no 'shoulds,' but a chance for insight. Remember, facing this ominous emotion takes tremendous courage. ▲

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*Isabel Stenzel Byrnes is 39 and has CF. She lives in Redwood City, California. You may contact her at: Isabel@usacfa.org. She recommends the book which supported this article, "Guilt" by Herant Katchadourian (Stanford University Press).*

## SUSTAINING PARTNERS



**CF Services Pharmacy**  
www.CFServicesPharmacy.com

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**A bequest from the estate of Pamela P. Post  
in honor of Kathy Russell**



# FOCUS TOPIC

## HOBBIES AND PLEASURE ACTIVITIES

### Roots

By Jeanie Hanley

When I initially went on medical leave, my first thought was that I finally had time to take care of myself the way I should. My second thought was, “How will I fill my days?” Up until then, my whole life had focused on work and family. Now that my children were in school all day, what would I do with those pockets of free time in between treatments?

Eventually, I realized that I had time to tinker on the piano and learn some new songs. Loving the sound of the piano, even with the occasional errant key, was such a joy and I played everyday and quite boldly, likely to my neighbors’ chagrin.

Over the years hobbies like this have come and gone; well, not completely but have been temporarily sidelined by new passions. Most of my hobbies have been centered around activities in which I can participate while being percussed and breathing in nebulized medications. So I found activities that interested me through the computer - writing, archaeology, reading, solving crossword puzzles, Sudoku, and Ken-ken and playing online Scrabble. My latest favorite is genealogy, uncovering relationships from the past and rediscovering connections with long lost relatives. Since my parents’ side of the family’s ancestry has been researched way back to the 1600s, I decided recently to begin redirecting this pastime to my husband’s family tree.



JEANIE HANLEY

Many years ago, before I had met my husband, John, his mother had given him a notebook where she had handwritten all that she knew of her family history. She stated that knowing your family roots was all the rage when the TV mini-series “Roots” was aired. Having accidentally come across the notebook more recently, I eagerly decided, with the help of a few genealogy internet sites, to construct the beginnings of their Irish and German ancestry. After working on my mother-in-law’s family, I saw that my father-in-law’s side was sorely lacking. After many conversations with him – a great historian with a great memory – he revealed all he

knew about his side of the family. Every piece of information, or beautiful little gems as I think of them, led to another person, another family, a new piece of the puzzle. Since I love solving puzzles, this hobby has been right up my alley.

Just as researching my family tree has resulted in contact with the Lopez family members I never knew existed, the same has occurred with John’s family. I have spoken to many of his family members, some of whom I knew but with whom I didn’t have much contact, others whom I had heard about, and some I had never known. Other families have contacted me via the ancestry sites when they see that we may have a connection. I just finished tracing back to the late 1700s the Irish side of

John’s family, to places like Cloonagh, Lenadoon, and Castlereagh, Ireland. Very cool names.

Knowing your world history well is very helpful when undertaking this hobby. I wish I had listened to my history teachers a little more. I had to relearn a great deal of Irish history, especially the Great Irish Potato Famine that appears to have affected most of John’s Irish ancestors. It was the driving force for their immigration during the 1840s to 1860s and also responsible for many early deaths. As they were all Roman Catholic, we can only surmise that most were impoverished laborers during the early 1800s. As in my family roots, no kings or

queens here. The upside is that the churches kept accurate records of baptisms dating back to the 1600s. In Ireland, the baptisms usually occurred a few days after the birth, so this provided a rough idea of their birth date. Records of his ancestors' immigration to New York through Ellis Island were also found, contributing more wonderful gems about their occupations and ages.

Some fun facts from my Hispanic family tree were uncovered in a treasure trove of letters written in Spanish during the early 1900s. One story that gave a personal and enlightening view of family history was the story of my great grandmother. During the Mexican Revolution she hid two political fugitives, who were fleeing from Pancho Villa's men, under her petticoat. It must have been quite large! Another pearl was discovering that my maiden name, Lopez, originated in the Basque area of northern Spain. Under religious persecution in

the 1500s, many people fled to other countries, especially to Mexico and other parts of the Americas. Coincidentally, it turns out that one of the CF mutations that I have is quite rare and found primarily in Ashkenazi Jews, who also populated the Basque region and fled during the religious crusades. Family history just got a little more fascinating.

During my treatments, I enjoy immensely poring over tidbits of ancestral information and sharing them with my in-laws, who, I believe, are equally enamored with this subject. The only caution I have for anyone who is interested in genealogy is that it is highly addictive and may be hazardous to your health! Long after my treatment has been finished, I'm still staring at the computer trying to make sense of some new information. When I'm at the computer for too long, I find that I breathe shallowly, which drives down my oxygenation.

To counter this one downside, I bought a beautiful rock with the word "Breathe" etched over it. I placed it close to me as a reminder to breathe deeply and, hopefully, to take a break from computer activities.

Delving into ancestry is not all a computer hobby. I find myself talking to and visiting more relatives than usual, collecting pictures and/or new information from them to add to the family tree and investigating further at places like the Mormon Los Angeles Branch Genealogy Library that has amassed centuries of information on families. I guess the best part is I can polish off three hobbies in one by relaxing with coffee along with a little chocolate treat, at the local coffee houses or bookstores, and surf the net for our roots. ▲

*Jeanie is 49 and has CF. She is a physician and a Director of USACFA. Her contact information is on page 2.*



## MILESTONES

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

### ANNIVERSARIES

#### **Birthday**

**Leslie Lynn Bryant Alford**  
Baytown, TX  
50 on January 25, 2011

#### **Kathy Russell**

Gresham, OR  
67 on April 17, 2011

#### **Carol Shepherd**

Fort Worth, TX  
53 on October 18, 2010

#### **Wedding**

**Kathy & Paul Russell**  
Gresham, OR  
46 years on March 27, 2011

#### **Transplant**

**Paul Albert, 51**  
Catasauqua, PA  
Bilateral lungs  
18 years on February 10, 2011

Greg Briggs, 57  
Jacksonville, FL  
Bilateral lungs  
14 years on April 30, 2011

### NEW BEGINNINGS

#### **Transplant**

**Adam Brockmiller, 26**  
Joplin, MO  
Bilateral lungs  
November 24, 2010



# My Hobbies and Pleasure Activities

By *Brian Weinstein*

This is my first article for *CF Roundtable* and I would like to start by introducing myself. My name is Brian Weinstein, I am 43 years old and I was diagnosed with cystic fibrosis when I was 1 year old. I have known no other life than with CF. I am a practicing general surgeon in Plantation, Florida. I love my job, although it does take a lot of my time – just ask my wife. My average work day is about 10 hours and, of course, there are the weekends. So when I saw that the focus topic was about pleasure activities and hobbies, I thought that this is something I could talk about. Unfortunately it reminded me that I needed to take more time for myself, but that is a whole different discussion.

To start with, I am writing this as I am on a flight from Florida to California for a combination vacation and medical conference. It is probably the only way that I would take some time off to get away. At least that is what my wife, Virginia, would tell you. We are going to tour wine country in Napa and Sonoma and then I will educate myself on the latest and greatest in hernia repair. It is a way that we can get the best of both worlds. I can get some relaxation, but I still feel that I am keeping current on the medical front.

So I thought about it when I wanted to write this article, what is a hobby? To me it is something that you like to do, want to do, don't have to be asked to do, and you feel relaxed and at ease when doing it. It is something that is fun. Well, the profession I have chosen as a surgeon fits the bill. I will tell you, though, that I take

my job and profession very seriously, so that's why it is so much more than a hobby. It is my life's work. There are so many highs and lows in my profession that you can't just call it a hobby; it is a lifestyle. So what does Brian do when not encompassed with work?

To begin with, I love to work out. Spending an hour or so away from the

n't look that way either.

In medical school, all we did was sleep, eat, go to class and study. "The Dog Pound" was the gym in the dorms. After class, a group of us would go down and "blast" before we would hit the library and study. I think that the exercise really helped my overall health while I was there. I



**BRIAN WEINSTEIN POINTS TO A ROAD WHERE HE AND HIS FRIENDS HAD JUST RIDDEN MOTORCYCLES IN WASHINGTON STATE.**

outside world does a body, and mind, good. Let's forget about all the health benefits, especially with CF, for a moment. I like to put my headphones on, crank the iPod with some cranking tunes and, for a while, it is just me and my body's potential. I started working out at a gym in college. I liked the results that I was seeing. Growing up with CF and always being skinny and looking "not healthy" was always an issue for me. When I first started going to the gym, I was starting to bulk up. I looked more normal. My self-image improved. Although I didn't take on the sick role, now I did-

had no major exacerbations while in medical school. Mentally, it helped us all, or we would go insane with all the studying without any type of distraction. I even tried to join a gym while in residency, but the time commitment was too great for most of that period.

When I finished residency and came down to South Florida, one of the first things I did was find a gym to join. Now I was paying for the membership, so I had better use it. I can tell you, I really do feel great when I am working out on a regular basis. Work is very busy, though, so going to the gym

late at night was getting difficult. My wife convinced me to get an elliptical trainer for the house for the late nights when I didn't want to go to the gym. It was a great investment. Now, even if I got out late, I could still get some cardiovascular and pulmonary workout in. I will admit there have been times when I have been less than enthusiastic about going to the gym. My CF doctor definitely will get on my case when I admit that I am not working out as much as I should. The whole point is that I have made it a part of my life and not only do I feel good, but it is good for me. You can't ask for a better hobby than that.

So that is for the daily release. What about when I have a whole day or weekend freed up? Well, then the alter ego comes out — doctor by day, motorcycle rider by weekend. I got the itch to try riding a motorcycle about 10 years ago, so I did it right. I took a motorcycle safety course and learned how to ride properly. I then went and bought my first motorcycle, a Harley Davidson Fatboy (yes, that is the name of a motorcycle). I would take daily local rides to feel more comfortable with riding. I progressed to weekend jaunts. My first long distance ride was from Ft. Lauderdale to the Daytona Bike Week. Wow, what a blast! Riding a motorcycle is not for everyone, but what a great feeling being on the road on two wheels.

A friend and I have progressed to week-long rides now. Our first one was a Harley rally in Virginia. We flew up to Maryland and rented bikes up there and rode through the Blue Ridge Parkway. Every year since, we have taken a trip. We rode with a group of guys to a rally from Florida to Tennessee and then back through the mountains of North Carolina. Last year my friend's son joined us for a trip through the Cascade Mountains of Washington State. I can't wait to see where we will go next.

Of course, traveling on a motorcycle does offer some challenges. I obviously can't bring my Vest® with me. I do try to keep up with inhalations and postural drainage so that my health is not compromised on these trips. Fortunately things have gone well and I have not had any problems while on these trips, but it definitely calls for being creative while "on the road." My friend has been very understanding in traveling with someone with CF and that makes it easier to plan trips. He had proposed a trip to

child. As I was busy with other things in my life, the leatherwork would get put aside. Every few years it gets resurrected and the joy it brings is immeasurable.

I would be remiss if I didn't mention my family. They are not a hobby but life itself. My wife of seven years, Virginia, has been there as the most supportive person in my life. I wouldn't be where I am in my life without her, and I am truly grateful that she is a part of my life. I couldn't go without talking about my little furry children.

“What about when I have a whole day or weekend freed up? Well, then the alter ego comes out — doctor by day, motorcycle rider by weekend.”

Colorado, but my doctor had recommended not going over 7000 feet in altitude. When I told my friend that, his response was, "Okay, let's see where we can go that will be good for you." You can't ask for better support than that.

Another hobby that I wish I had more time for is leather carving. This hobby definitely has a connection with my choice of career. I love to work with my hands. Surgery allows me to use my hands in a way to cure disease and help people. Leather carving is another way to use my hands to create art. I never thought of myself as an artistic individual. The things that can be made by leather carving are quite stunning. I use patterns (again I am not that artistic) and using tools and my hands, can make something out of a blank piece of leather. The satisfaction that comes from looking at a finished product and saying, "I made that" is beyond words. My parents got me my first kit, when I was a

Just ask anyone; I can't have a conversation without mentioning Belle, Rocky, Gizmo and the newest addition to the family, Tiny. They are all Maltese that will steal your heart with the unconditional love they give.

No hobby is worthwhile if there is not enough time for family. I think that part of the reason that I don't spend as much time with my hobbies is that work dominates my time, but I would never want to compromise the time with my family. That is what is most important.

Well, there you have it. These have been a few of the things that I do for pleasure and relaxation. I hope that I haven't rambled too much. I enjoyed sharing with all of you and I hope that I can do it again soon. ▲

*Brian is 43 and has CF. He is a general surgeon who lives with his wife, Virginia, and their four Maltese in Plantation, FL. He can be contacted at: [Brian.Weinstein@att.net](mailto:Brian.Weinstein@att.net)*



# How My Hobby Improved My Health

By Bracha Witonsky

As a little girl growing up with cystic fibrosis, I loved to sing. I had a gorgeous soprano voice and always sang my heart out. In school, I sang solos in plays, and in camp I often was chosen to perform.

Eventually I became a teacher, which required daily use of my voice. In addition, the increasing number of daily nebulizer treatments and the resultant coughing, took quite a toll on my vocal cords. I was often very hoarse, especially on Mondays, when I would return to the classroom after having rested my voice all weekend. I tried lots of natural remedies like drinking special teas, sucking on various lozenges, and even going for speech therapy and seeing the top notch ENTs (ear, nose and throat docs) that specialize in vocal cords but nothing succeeded.

It was frustrating. In my mind a raspy, hoarse voice was indicative of having CF. In those days, I was keeping my CF a total secret from everyone, so being constantly hoarse and having a very raspy, nasal voice was a giveaway to my secret illness, CF.

I knew that medically there was nothing more I could do. I kept trying things in search of finding the ultimate cure. I had heard of a voice teacher in my community who taught

non-singers to better utilize their voices. To encourage her voice students, she would invite them to perform in a concert she organized once a year. I enjoyed singing and talking, and I wanted to stop getting hoarse. It was then that I decided to take private voice lessons with this woman, Malky Giniger. From her, I learned to speak

talk and sing effortlessly, without having to use all my energy in trying to make myself heard.

An interesting point was that when I first started one-on-one voice lessons with Malky Giniger, it had been embarrassing because I could barely push out three notes. Now, I can reach numerous octaves. People have told me that I sound like a new person. I learned so many amazing voice exercises and techniques from my singing lessons. I feel much more confident in my new voice, enjoy the ability to sing and can feel the difference in my breathing. Another benefit has been to use these techniques to relax and get rid of any anger I might have.

But most important and most unexpectedly, my PFTs have shown a marked improvement! It simply amazed my doctors. Who would have ever imagined what simple voice lessons could accomplish?

Now I am a singer. I sing on stage in front of audiences of hundreds of people, and I am recorded on many DVDs and CDs. I continue to take voice lessons once a week, for an hour. I consider it one of my

medical treatments, and a hobby. ▲

*Bracha Witonsky is 34 years old and has CF. She is married with two healthy children. She can be reached at [cffamilytimes@gmail.com](mailto:cffamilytimes@gmail.com).*



BRACHA WITONSKY SINGS.

from my stomach, using all my abdominal muscles and resting my vocal cords. Not only did this cure my frustration, but I also regained my sweet, high-pitched voice that I had as a little girl. Plus, I was now able to

“I learned so many amazing voice exercises and techniques from my singing lessons. I feel much more confident in my new voice, enjoy the ability to sing and can feel the difference in my breathing.”

## CAREGIVER STORIES

### Welcome to my Garden

Welcome to my garden  
It is a mother's garden  
Tended with love and care

Enter my garden  
And it looks like any other  
Shades of lavender, tender green, blushing pinks  
But look a little closer  
Beside the familiar are the unordinary  
My tools to fight off the beasties which devour  
the young,  
the tender,  
the vulnerable  
With an insatiable hunger  
Like the garden pests of slime and mouth.

My garden is different and yet you might not have noticed  
It requires a special patience,  
a kind of not knowing,  
a deep letting go,  
a courage  
Are you a gardener of like kind?

As I cultivate my garden  
watching my children grow  
These necessary implements are for my CF child,  
A delicate lily who requires a gardener's arsenal  
You may have never tended a garden such as this  
Or perhaps you have

This is where  
The Miracle Grow is applied at every meal  
Chemical fertilizers and pesticides abound  
Where tears are the season's first watering  
Where the pulsating compressors and  
A child's persistent cough fills a mother's weary ear  
Where there is a name to your child's condition, cystic fibrosis  
And it is all behind the garden gate,  
So you probably did not know.

It is summer now in my garden  
I have loved and worked hard and used my tools religiously  
And my lily has grown  
Holding my hand  
Making me laugh  
Hugging me tightly  
Hugging me often  
Loving me so dearly  
She is breaking the odds  
Blossoming through her struggles  
Beauty and Wisdom  
give her Grace.

May it forever be summer  
When the glorious sun and rich earth  
nurtures my exquisite lily  
And her sister of gentle beauty.



PHOTO BY MARGARET MYERS

May it forever be summer in this garden  
It is a mother's prayer  
May this season never change  
In my garden of love.

Yet this is the way  
Seasons do change  
Gardens mature  
And love knows this

So if you also see me gardening during  
the harvest moon  
the winter solstice  
the emerging spring  
Help me find the path  
Gently remind me of  
the special patience  
the kind of not knowing  
the deep letting go  
the courage.

Hold my hand  
Make me laugh  
Hug me tightly  
Hug me often  
Love me dearly.

- Robin Modlin, July, 2002

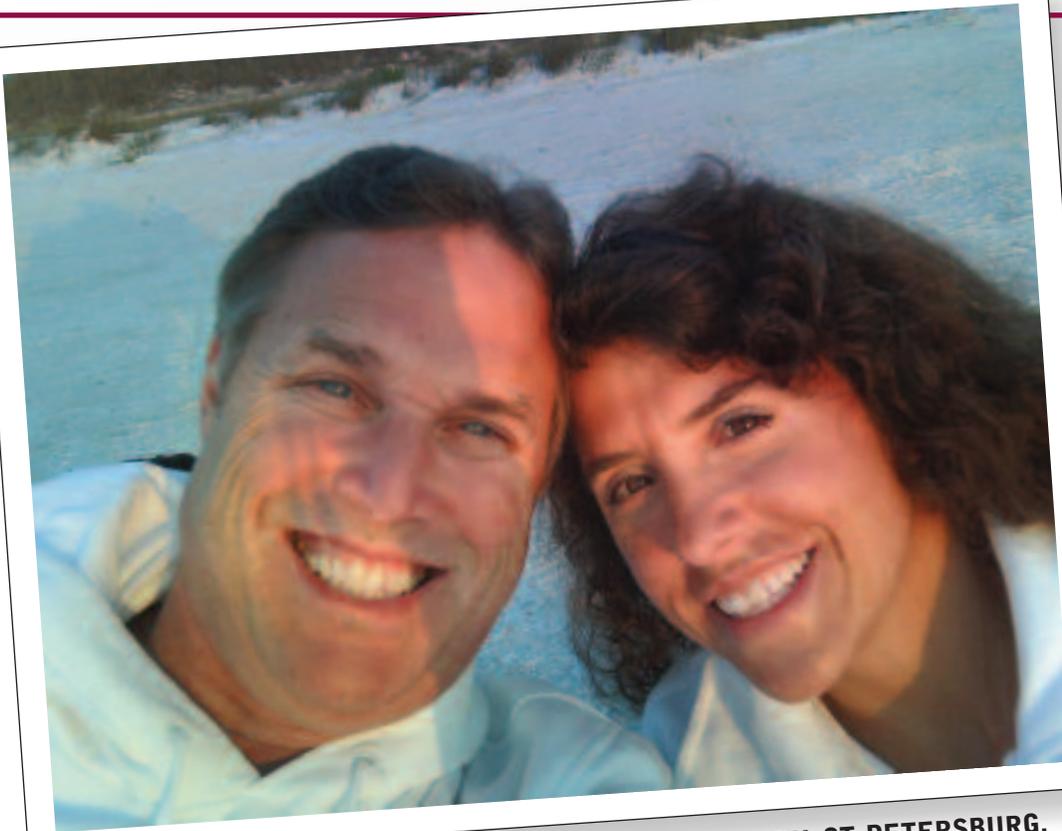
# FROM OUR FAMILY PHOTO ALBUM...



**BRIAN WEINSTEIN,  
HIS WIFE, VIRGINIA,  
AND HIS MOM,  
SHERYL, WHEN HE  
FIRST GOT HIS  
MOTORCYCLE.**



**EMILY HEISE AT THE NIABI ZOO IN COAL VALLEY, IL, SUMMER 2010.**



**MARK AND JENNIFER HALE AT SUNSET IN FT. DESOTO PARK, ST. PETERSBURG, FLORIDA.**



**BRACHA WITONSKY AND HER TWO DAUGHTERS, SHAINA AND SHULAMIS ZAHAVA, DRESSED AS ICE CREAM SUNDAES ON PURIM, WHICH FELL ON SUNDAY THIS YEAR.**



# Volunteering Is My Hobby

By Nicole Matthews

**H**ello, my name is Nicole Matthews. I am currently 22 years old and I was diagnosed with CF at 22 months of age. I have been dating the same man for the past four and a half years. His name is Christopher. We have recently moved into our first apartment together and are looking forward to the next step of our lives. I graduated college with an associate's degree in liberal arts and science, and I now work full time at a local car dealership. I do not know the meaning of relax, but I do know to live everyday to its very fullest and to enjoy every moment. My CF is more with my digestive tract than my lungs. Not only do I have CF, but I also have a gluten allergy, rheumatoid arthritis and sinusitis.

I have been involved in so many hobbies and so many activities, it's almost hard to keep track of them all. I have been an Active EMT in the Hillcrest Volunteer Fire Company for four years, and I have held the lieutenant's position on our ambulance for two of those years. Being in the fire company can be very difficult, at times, and frustrating; but then you have times when you enjoy it and you are glad to help anybody. I have delivered a baby, I have performed CPR, I have watched homes burn, and I have seen many vehicle accidents.

My family is also very involved with the fire company; my father and my mother have been involved in the company for over 25 years, my sister for two years. My dad's parents, along with my aunts, uncles and cousins are involved too. I dragged Chris into the fire company as well. I am only an EMT, due to CF and the complications that could arise from being a fireman. It is very frustrating watch-

ing all my friends and family gear up, ride the fire trucks, and conquer the fires. I would love to be with them and fighting beside them, but I am also very happy watching from the sideline and taking care of victims.

The fire company is not my only volunteering. Every Saturday from October to the end of March I ice skate with my sister and my father with the ice skating programs "SABAH" and "Gliding Stars". Both of these programs

I do volunteer a lot, but I do also know how to enjoy myself and have fun. My family has about 120 acres of land in Cuba, New York where we dirt bike and four-wheel across. When out at camp, we know how to ride, eat, drink and just have plain old fun. We truly enjoy ourselves out there; it is so peaceful and the scenery is beautiful. Chris and I set up a platform for our tent to sit on, so we have a little spot of our own. If we're not out in Cuba, we are at a campground



**CHRIS KIEFHABER AND NICOLE MATTHEWS.**

help handicapped children and adults learn how to ice skate. I have participated in these programs for over 10 years, and I enjoy every minute of it. I am an on-ice volunteer for SABAH and a teacher on-ice for Gliding Stars. To watch the smiles on the kid's faces every Saturday is priceless, and to be able to help disabled children ice skate is breathtaking. I was once one of those kids first learning and having my own volunteer, because of CF. But now it's me helping them and teaching them. I know that being there I make a difference, and that my appearance and knowledge are helpful.

somewhere in Alleghany.

To me having CF doesn't always mean staying home. I may have a bad cough caused from a sinus infection that worked its way into my lungs, but when I ice skate it eases my cough. When I four-wheel I can feel some of the secretions loosening in my lungs. I try to stay as active as possible because, sadly enough, I know that someday I may not be able to be as active as I am now. Thank you for letting me share my story about my hobbies! ▲

*Nicole is 22 and has CF. She lives in Orchard Park, NY.*



# Jamming On Skates

By April Thompson

**M**y name is April Thompson. I used to be a Green, until I got married. I am 30 years old and live in Wheeling, WV. My journey has been hard, just like every other person with CF. My hobby is exciting. I am a roller girl! Yes, my new love is Roller Derby. It is good for the social and physical aspects of my life. It is very hard at times, but I can keep up with the best of them.

This is not your typical hobby, so I thought I would share. I have always had a love for roller skating. Last August my husband saw a posting on Facebook about a roller derby league forming in our area. He told me about it, since he felt it was “right up my alley”. I was so excited that I emailed my info right away. The next day I had the packet of info filled out, and I was joining the league!

Roller derby is a full contact sport on roller skates, for anyone who doesn't know. I have been training on Tuesdays and, sometimes, Sundays since then. Practice usually lasts about three hours and it is draining. We actually had to take a test to stay on the team. It was things such as how to fall correctly,

“I am happy to say that I made the all star traveling team. That felt great to know that I could accomplish something like that.”

jumping, weaving, hitting etc.

I took the test in January. I was so happy to find out that I had passed! I scored 145 out of a possible 160. Yes, I rocked it! Go me and my bad CF lungs! We split into teams and the top 14 got the chance to be on the traveling team. I am happy to say that I made the all-star-traveling team. It felt great to know that I could accomplish something like that.

My favorite position to play is what is called a “jammer”. That is the person who scores all the points, and gets all the crowd cheers. You have to be fast and agile for this position, which suits my style. The object is to get through what is called the pack. That is the group of girls in front of you, trying to stop you from passing them. This is where you get hit! The pack goes on

the first whistle and the jammers go on the next whistle. Then all the fun starts! You want to be the first jammer through that pack in order to get control of the jam. A jam can last for two-and-a-half minutes. Sometimes it lasts for 30 seconds. It all depends on that first girl through; she has all the control. She can call off the jam at any time. The whole bout is 60 minutes, split into two 30 minute halves.

Roller derby is not staged – you get hit and you fall down. You get bruises, but it is tons of fun – at least it is for me. It is very physical and demanding, but I love it! ▲

*April is 30 and has CF. She lives in Wheeling, WV. You may contact her at: meangreenie26@yahoo.com or on Facebook.*



## CF Living

**C**heck 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!



# WELLNESS

## Go With The Flow

By Julie Desch, MD

This issue of *CF Roundtable* has a focus topic of “hobbies,” so you’ve probably been reading about what others with CF enjoy doing in their spare time (ha...spare time... right).

Instead of boring you all with my forays into the art of javelin catching, I thought I would instead discuss why we humans pursue hobbies, and why they are good for us.

The concept of “flow” is all the rage in psychology today. According to Wikipedia, “flow” is the mental state of operation in which a person is “fully immersed in a feeling of energized focus, full involvement, and success in the process of activity.” It is the feeling of focused, single-minded immersion in a process of performing, or learning, or doing something. For example, as that javelin is arching toward me, I am completely focused on its position in space, speed of travel, and my position to the exclusion of everything else...time, emotion, thought...everything. Really!

The easiest descriptions of flow to understand are those that occur during various sporting activities. Athletes are described as “in the zone” during flow. In these moments, their attention and skill are exclusively aligned with the task at hand. The sense of time and even of being a separate individual disappears as the athlete merges with his/her performance and is completely “in the moment.”

Not only does the state of flow lead to incredible performances, it is also an extremely positive experience. During flow, emotions are both posi-

tively energized and channeled toward the task at hand. The hallmark feeling of flow is spontaneous joy while performing a task that perfectly matches high levels of skill with equally high levels of challenge.

But you don’t have to be Kobe Bryant to experience flow. Musicians and other performers understand this concept. Artists readily achieve this state as they are engrossed in a project. I know from experience that meditation can induce this state. My sons would almost certainly advocate video gaming as a source of flow. Most likely, the people who have written

about their pet hobbies are attracted to them because they encourage the state of flow.

So why do humans gravitate toward the state of flow? For the same reason we tend to do anything that produces intense feelings of enjoyment. Not only is flow a positive experience in the moment, it also allows for optimal performance and skill enhancement. One of the essential ingredients for the achievement of flow is that one’s skill level must be continually challenged. As a result, skill levels improve. Then, to maintain flow, one must seek continually greater challenges. This creates a positive feedback loop, with the result being growing feelings of competence and efficacy.

Is this an important idea for adults with cystic fibrosis? Well, since I’m writing about it, you’ll not be surprised to hear that I think it is incredibly important! The unpredictable and cyclical nature of living in a body with CF can quite easily lead to chronic anxiety and even depression. We all understand this. CF sucks enough without layering on anxiety and depression, right?

Interestingly, flow is the exact opposite state from anxiety and depression. Anxiety and depression stem from chemical imbalances in the brain, of course. But the thoughts and emotions that accompany this imbalance are usually centered on fear...fear of not being in control, fear of loss of health, fear of death.

There is no room for fear when you are in flow. In fact, your brain is so occupied with whatever you are

*The hallmark feeling of flow is spontaneous joy while performing a task that perfectly matches high levels of skill with equally high levels of challenge.*



JULIE DESCH, MD

doing during flows that there is no room for anything else at all. You lose sense of time, of bodily functions, of anything extraneous to the task at hand. A daily dose of flow can do wonders to keep depression at bay.

### Setting Up Flow

There are three important rules to follow when trying to encourage a state of flow. First, there must be a clear set of goals for the activity. This gives direction and structure to the activity and provides motivation.

Second, there must be a good match between the challenge and your perceived skills. You must have confidence that you can do what you set out to do. It can't be too easy, though. That would lead to boredom. It also can't be too difficult. This would lead to frustration. Flow arrives when your skills set is stretched *just enough*. You must channel your inner Goldilocks.

Finally, the task must have very clear and immediate feedback. This allows for minute adjustments to allow continuation of the flow state.

### Examples

Not surprisingly, the activities that have brought me into flow have changed over the years. When I was younger, I most definitely entered flow when I was challenged by a difficult exam in school. Weird, I know. But sitting down to take a test, knowing that I was prepared and knew the material cold, I entered a zone. I was challenged, but I was confident. It was actually fun.

As a pathologist, I could occasionally feel flow when I was "slamming glass" (a fond way of referring to reading slides.) An especially interesting caseload that would challenge my memory and reasoning might take me away for hours without my noticing the passage of time. It didn't even feel like work.

An easy place for me to find flow has always been in the gym. Perhaps this is why I have always loved exercise. When I am in the gym, completely confident in what I am doing, I am not "sick Julie". I'm not even Julie. I just am. I'm pushing my limits, focusing, achieving.

I can also get into flow when I am learning about something that 1) I am interested in, and 2) is complicated enough that I have to completely focus to understand. This is my current preferred pathway to flow.

Where do you find flow? Wherever it is, spend time doing it. It's good for your brain, and for your spirit.

*Author's Note:* After watching a recent episode of "1000 Ways to Die," I have retired from the sport of javelin catching. ▲

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*Julie is 50 and is a physician who has CF. You may contact her at: [jdesch@usacfa.org](mailto:jdesch@usacfa.org)*

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## Information from the Internet...

*Compiled by Laura Tillman*

This issue brings a potpourri of articles from the Internet

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### NEWS RELEASES

#### Extended Benefit With Bronchitol in Second Phase III Cystic Fibrosis Trial

Pharmaceutical company, Pharmaxis, announced positive first results for the open label component of its second international Phase III trial of Bronchitol in people with cystic fibrosis. The key findings were: 1) Lung function change (FEV<sub>1</sub>) for those participants treated with Bronchitol for 6 months was 8.2% and this was main-

tained out to 12 months (FEV<sub>1</sub> improvement of 8.2%). The withdrawal rate in the open label phase was 7%. 2) Subjects who were switched from control to Bronchitol at the end of the first 6 months had a 6.3% improvement in lung function relative to baseline at the end of 12 months. The trial objective was to determine the safety of Bronchitol in patients with cystic fibrosis following twelve months treatment and to assess the long term effects on lung function. This clinical

trial of Bronchitol was conducted in two phases. The first six months was controlled and blinded and designed to assess efficacy and safety. The second six months was open label, unblinded and not controlled. Patients initially randomized to the control group were switched to receive Bronchitol during the subsequent six month open phase. In all subjects in the open label phase, the most commonly reported adverse events were haemoptysis, headache and cough. Bronchitol is designed to hydrate the airway surface of the lungs, and promote normal lung mucus clearance. Bronchitol is a proprietary dry-powder mannitol, precision formulated for delivery to the lungs through an easy-to-use, pocket-size, portable inhaler. Once inhaled its five-way action on mucus helps restore normal

*Continued on page 27*



# A DEEP BREATH IN Connecting from 3 Feet Apart

By Debbie Ajini

In February, the show Grey's Anatomy featured a young man with CF about to get new lungs; however, there was a small issue. When they realized he had a girlfriend who also had CF, they weren't going to give him the new lungs! They said it was too risky and the girlfriend would just end up giving her CF bacteria to the boyfriend's new lungs. Now, there are a few hot topics in this little story and many of my friends have asked me what I think. Transplant ethics aside, I want to focus on the "3 Foot Rule". From about.com: "The rule is very simple — stay three feet away from people who have any kind of respiratory infection, and from other people with cystic fibrosis. Why three feet? Because that is the distance that germ-ridden droplets are thought to be able to travel when an infected person coughs or sneezes." Many of them were not aware of these guidelines that have been set forth in the CF community by the powers that be.

The guideline sounds simple enough, especially if you have grown up with it always being that way. However, I knew what it was like BEFORE. When I went to clinic it was always a time to see old friends. I went to CF camp and we certainly were a lot closer to each other than three feet. I remember the "good old days" of running around camp with other kids, sleeping next to them, getting therapy next to them etc. Of course, we now know that probably wasn't the best idea. Yet, at the same time, I am grateful because now I know the value of sitting on a

bed with another CF friend, eating snacks and talking about the things that only we would understand. I know what it is like to hug them at a CF friend's funeral, knowing they really "get" how hard it is. I know



DEBBIE AJINI

*Thankfully technology is moving in a way that is making it really easy to get connected with other people with CF around the state, country and world!*

what it is like hanging out and laughing and coughing and having it all feel so normal. We were normal when we were with each other. That connection is so hard to describe unless you have experienced it first hand.

I was first introduced to the risks

of cross-infection, like many of my peers, at CF camp. What started out as separate rooms evolved into separate camps and it ended in there being no camps at all. That is a whole article of its own! Suffice it to say, I was not happy at the beginning or middle or end of this process. Now that I am 40, I can look back with more of an objective eye and I do understand there was something to the concern.

I have no scientific evidence but I can look back and see that my frequency of hospitalizations/IVs did seem to go up when I was regularly around others with CF (e.g. family and camp). At points with less interaction I tended to get infections less often. I have no idea if it is coincidence or I just became more aware of the risks of cross-infection and, therefore, was more careful, which resulted in fewer exacerbations. It's a chicken and egg dilemma I will never really know the answer to. It does give me something to ponder though.

What I do know is what is right for ME now, despite its social disadvantages, is to adhere to the 3 foot rule, especially since I have B. cepacia. I DO NOT want to expose anyone to it. I would feel horrible if they got it from me. Heck, I even apply the 3 foot rule at family gatherings, especially winter ones where the germs run rampant. Everyone knows to ask if I am hugging that day or not. If not, we will bump elbows.

Thankfully technology is moving in a way that is making it really easy to get connected with other people with CF around the state, country and world! That is definitely better than nothing.

Facebook and blogging have become the new support group for people with CF. I have met many new people that way. *CF Roundtable* keeps us connected. Ironically, I have never met most of our board members face-to-face and I probably never will. I still get sad about that but, for the most part, I accept it.

I wonder, for those CF adults who have never really been around other CF adults, if they feel like

*Knowing someone else out there gets what you are going through is very comforting.*

they are missing something? Support is a vital part of survival. It doesn't matter how you get it – just that you do. Knowing someone else out there gets what you are going through is very comforting.

There are still a few occasions where I see my friends with CF. I do use the 3-foot rule even with those people I have known for years. It is a challenge, but we understand it is for our own good. It is not how I want things to be, but such is life. So, I keep my distance and do my best to treasure the connection that IS there. I know this connection is better than none. Even from 3 feet away!▲

*Debbie is 40 and has CF. She is a Director of USACFA. Her contact information is on page 2.*

## Announcements



### VOLUNTEERS NEEDED FOR STUDIES AT NIH

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

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

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



## 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](http://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.





## I Did Not Ask For This

By Jennifer Hale

I was born a bouncy, vibrant, cuddly baby girl. Perfect in every way with a future so bright, like the song goes, “you gotta wear shades”. But the bright future was slowly presenting a huge black dot on the horizon. At the age of 2, I was diagnosed with cystic fibrosis (CF), a genetic killer of a disease, which is slow and merciless in its quest to consume and kill me. I was also born a fighter with a laugh that echoes throughout the heavens above and a positive attitude that does succumb to the dark side now and then.

I did not ask for this disease that is slowly killing me and robbing me of the very breath that I need to sustain my life. I did not ask to be consumed with mucus that is sticky and looks and feels like wet cement. Its very existence inside me is hardening me up from the inside, like clay hardens into a statue. But this “clay-like” substance is not molding a beautiful statue that someday may memorialize a great human being, a symbol of freedom or a monument. This substance is suffocating me and slowly robbing me of my existence on this earth.

I did not ask for CF, but I will not go down without a fight. I ask myself, at times, do I have the fight still in me? Like an amateur boxer going 15 excruciating rounds against the World Champ, can I answer the bell one more time? What choice do

“I did not ask to be consumed with mucus that is sticky and looks and feels like wet cement.”

I have? This is my lot in life, but I did not ask for this. Every sickness is a set-back in lung function. How many times can you hit the reset button and have it reset to the baseline lung function I need to maintain? I strive to maintain a baseline lung function that can easily plummet due to one tiny virus.

I did not ask for this, but I will do what I can to stave off this dreadful disease. I will look to the ocean for my strength and look to my husband for the love and courage to

keep fighting. I was taught to fight, to never give up and that is a lesson I will take with me to my grave. But after each round I am so beaten up. I wonder how many times I can answer the bell that says the next round is ready to begin. Ah, the sweet sound of beginning again. Beginning again after each sickness that sets me back so far I wonder if I can even see the end of the road.

I did not ask for this lung disease that offers an average life expectancy of 37 years and soon I will be 39! I did not ask for this because when you can't breathe, it sure makes it difficult to exist and live life. As they say, if you do not have your health you do not have much. I did not ask for this, but who would? So I will keep on keeping on and judge myself not on what I can't do but what I can do. I will find my happiness in my sunny surroundings, the gritty sand on my feet, and the sun in my eyes and a future so bright I “gotta wear shades”. ▲



JENNIFER HALE

*Jennifer is 39 and has CF. She lives in St. Petersburg, FL. She can be contacted at: beachbum7260\_golf@yahoo.com.*

lung clearance mechanisms. Bronchitol has received Orphan Drug Designation and fast track status from the US Food and Drug Administration and Orphan Drug Designation from the European Medicines Agency. <http://www.irasia.com/listco/au/pharmaxis/press/p101216.htm>

**Novel Drug Offers Hope For Early Intervention In Cystic Fibrosis Patients**

Cystic fibrosis patients with normal to mildly impaired lung function may benefit from a new investigational drug designed to help prevent formation of the sticky mucus. Called denufosal, the investigational medication can be given early in the CF disease process, and may help delay the progression of lung disease. Denufosal belongs to a class of drugs known as ion channel regulators. These drugs help balance the flow of ions through cell membranes, helping normalize the airway surface hydration and mucus clearance impairment present in CF patients. Denufosal works by increasing chloride secretion, inhibiting sodium absorption and increasing the beat

frequency of the tiny hairs, or “cilia,” lining the airways to clear mucus. Combined, these effects enhance airway hydration and aid in clearing mucus. The drug is different from other CF medications, which primarily treat the symptoms rather than the underlying causes. <http://www.medicalnewstoday.com/articles/211456.php>

**ALSO SEE:**

**TIGER-1 Denufosal Phase 3 Trial for Cystic Fibrosis Published in the American Journal of Respiratory and Critical Care Medicine** <http://tinyurl.com/24t7gtg>

**Denufosal Tetrasodium in Patients with Cystic Fibrosis and Normal to Mildly Impaired Lung Function.** Frank J Accurso, Richard B Moss, Robert W Wilmott, Ran D Anbar, Amy E Schaberg, Todd A Durham, Bonnie W Ramsey, and the TIGER-1 Investigator Study Group. Am. J. Respir. Crit. Care Med., Volume 183, Number 5, March 2011, 627-634 <http://tinyurl.com/2bzkkw>

**Phase 3 Study Of VX-770 Shows Marked Improvement In Lung Function Among People With Cystic Fibrosis With G551D Mutation**

VX-770, an oral medicine in development that targets the defective protein that causes cystic fibrosis, showed promising results in a Phase 3 clinical trial. The trial was designed to evaluate patients who carry at least one copy of a CF mutation called G551D. Patients who took the drug showed a marked improvement in lung function. They also showed improvement across all key secondary endpoints in the study, including reduced likelihood of experiencing a pulmonary exacerbation, decreased respiratory symptoms and improved weight gain. In addition, average sweat chloride levels of patients on VX-770 dropped toward normal levels. <http://tinyurl.com/4v98atp>

**Mpex Initiates Phase 3 Clinical Trial Program With Aeroquin™ For The Treatment Of Chronic Bacterial Infections In Cystic Fibrosis Patients**  
Mpex Pharmaceuticals, Inc.

*Continued on page 31*



*Benefactors*

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## Secret Identities Can Fight Crime, Evil And Disease

By Emily Heise

Superheroes, secret agents and mystical characters harbor secret lives constantly. They are consumed by the double: two careers, two identities, two worlds creating their lives. We see it all the time in television and movies; characters putting on a front to appear as simple family members, high school students or respectable members of the career world when, in actuality, they are secret agents or mystical creatures and masked superheroes protecting the world's secrets and fighting crime or evil. Yet, is it possible to go your entire life thinking and making others believe you are one person when secretly there's something about you that's hidden away, deep inside where no one can see it?

I'm not a secret agent, a vampire, a werewolf or a masked crusader defending the law, yet I was living a double life. Though my 24-year-old body appeared healthy and strong on the outside, I was hiding a secret, one so deep inside it was rooted way down in my genes. However, unlike the actors who successfully maintain their secret identity, my secret was discovered.

Growing up I was constantly living out my double life, dressing up in frilly dresses and a crown, dancing around my castle. I was a veterinarian rescuing the lives of animals or a world-famous discoverer uncovering the remains of a dinosaur. I'd explore my neighborhood as a cowgirl on her trusty steed, my posse right beside me. Wherever my imagination or the imaginations of my friends roamed, I could keep up with them, running as fast as I could, never having to stop

and catch my breath. I was never left behind, and running and childish playing hid my secret well.

However, when I started school, a tiny detail slipped from my body, yet I never thought anything unusual about it; it is part of who I am. My



**EMILY HEISE AT "THE BEAN" IN MILLENNIUM PARK IN CHICAGO.**

height and petite size became a joke among friends, especially when one of my best friends was six feet tall. Sure, I was always the shortest of my friends, having to constantly sit in the first row during classes or stand in the front at school concerts so my parents could snap photos of my smiling face; but I was just taking after my mom's side of the family, settling into my short genes as the smallest of three children.

I was successfully able to main-

tain my ordinary identity in middle school and high school. Not even daily physical education could reveal my secret identity. I could run, withstand a tough workout and maintain my stamina just like everyone else, one deep breath at a time. Four years of cheerleading didn't even shed one clue about my secret to anyone, including me. I was able to jump and kick breathlessly, cheering and yelling strong. I was a base lifting girls in stunts and I also flew through the air never once having to stop and catch my breath. I was always the one who needed to slow down and wait for everyone else to catch up.

I was healthy and conscious of my health, my diet reflecting the food pyramid with a good balance of fruits, vegetables, dairy and protein. However, for my petite size, I could eat almost as much as the football boys I cheered for. No one knew where I was storing the food because it never showed anywhere on my body. However, unlike the boys, I looked two months pregnant after eating an orange or snack sized bag of potato chips.

I lived and learned my freshman and sophomore years at Bradley University, maintaining a normal diet and exercising to relieve the stress of college courses – no one ever suspecting I was hiding something. During my junior year, my secret started to surface. One minute I would be fine, laughing, sitting in class or doing chores around my apartment, the next I would be doubled over in pain clutching at my side and lower chest with what felt like massive heartburn.

I would lie stretched out on the

floor or in my bed trying to catch my breath and not wanting anyone to come near me or touch me. Every little attempt to help seemed to send another explosion of pain through my body. This negatively affected my social life and daily events.

I was scared to go out with my friends for fear my secret life would emerge, sending pain through my body that would cut my night short. When I did go out and was struck by pain, as patient as my friends were, it was frustrating for them to have to stop the evening to take me home.

Enjoying perks of young adulthood like an alcoholic drink with a meal or a celebratory drink when a friend turned 21 was out of the question, as it would spark unwanted pain and acid reflux. I became the permanent designated driver. I would be out of my mind trying to eat spicy and greasy foods. The blander the meal the better and I could enjoy an evening pain free.

This was the very beginning of my two lives merging into one. Eventually the pain became more and more frequent and unbearable. During my first doctor's visit I underwent an ultrasound and a GI Series. They discovered I had gallstones and a massive case of acid reflux. I was stubborn and tried as hard as I could to keep my secret hidden, putting off the surgery to remove my gallbladder. However, after a night at the movies, I woke bright and early to a pain attack and underwent emergency surgery to remove my gallbladder and crush the quarter-sized stone that was stuck in my biliary tract.

After the surgery, my secret started to develop and reveal itself more and more. I developed a dry, hacking cough that no cough suppressant, throat lozenges or tablespoons of honey could cure. I would cough so deep and hard that it became impossible for me to keep anything down, including mucus. I could cough up

“ Though my 24-year-old body appeared healthy and strong on the outside, I was hiding a secret; one so deep inside it was rooted way down in my genes. ”

cupfuls of mucus in a day simply by laughing too hard or by moving after sitting or lying down too long. And even though I continued to have my healthy appetite, I lost an extreme amount of weight without a reasonable explanation.

Being athletic, I noticed that walking up stairs became a challenge. I would become short of breath and need to take a rest after hitting the top of the stairs and, of course, the nagging cough would start. It was impossible to sneak up on anyone and embarrassing when everyone I interacted with thought I was sick.

After surviving four years of college, two years of doctors' visits began. Though my secret life was slowly emerging, no one could put a name to what I was hiding inside. Since my gallbladder was removed there was no reasonable explanation as to why my liver enzymes remained at an abnormal level - almost double the normal range. Every month I had the ritual of blood work done, slowly starting to feel like a human pincushion. My doctor sent me to a pulmonary disease specialist who attributed my irritating cough to severe exercised-induced asthma, allergies, sinus drainage and reflux. However, the regimen of prescribed inhalers didn't calm the irksome cough and I began waking up during the night coughing for hours straight.

I underwent two ERCPs (Endoscopic Retrograde Cholangio Pancreatography) because my doctor suspected stones and sludge blocked my common bile duct, causing the elevated liver enzyme levels. The first ERCP

was unsuccessful and traumatizing, as I stopped breathing twice. However, the second ERCP was a success, draining all the gunk blocking my duct, yet my liver enzymes would still not go down.

Unable to determine my secret, my gastroenterologist and my pulmonary disease specialist decided to send me to the detectives at Iowa City to see if they could crack my secret from the vault that was my body. Two doctors later, numerous chest x-rays, a liver biopsy, a sprinkle of pulmonary function tests, a variety of blood tests ruling out about every possible disease known to man, they discovered I have a fatty liver and pancreas and my doctor suggested I have a sweat chloride test performed.

Within days my secret was discovered and after close examination of all my x-rays and even more tubes of blood, I was introduced to cystic fibrosis, clubbed fingers and their partner in crime - *Pseudomonas*.

After two long years my two-word secret to my double life was finally diagnosed as cystic fibrosis. Unlike modern day superheroes, secret agents and spies who can maintain their secret identity and keep it camouflaged among daily life, I couldn't keep my identity confidential. And though I have a vibrating vest instead of a cape and misty breathing treatments as a disguise, I'm fighting *Pseudomonas* everyday to bring about a better breathing tomorrow. ▲

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*Emily is 24 and has CF. She lives in Geneseo, IL. You may contact her at: [eheise@mail.bradley.edu](mailto:eheise@mail.bradley.edu).*



## 24th National Cystic Fibrosis Family Education Conference

# Cystic Fibrosis in the Spotlight: Taking A Leading Role

*July 29 - 31, 2011  
Sofitel San Francisco Bay Area*

CFRI's Education Conference supports families, adults with CF, health providers and caregivers. Clinicians, researchers and therapists bring their expertise from across the country and abroad.

For more information, contact CFRI at (650) 404-9975 or [cfri@cfri.org](mailto:cfri@cfri.org)  
To register, visit [www.CFRI.org](http://www.CFRI.org)

## CF TEEN AND ADULT RETREAT

*July 31st - August 7th, 2011  
Vallombrosa Center ■ Menlo Park, CA*

# CFRI High: Learning to Live Class of 2011

**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 for those who drop in for a meal only. Overnight accommodations and

transportation are the responsibility of participants. Scholarships are available for those to cover registration and accommodation.

**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.

**For more information,** contact Cystic Fibrosis Research, Inc. (650) 404-9975 [cfri@cfri.org](mailto:cfri@cfri.org)  
<http://www.facebook.com/home.php#!/group.php?gid=2342719557>

announced that it has initiated its Phase 3 clinical trial program with Aeroquin™ (MP-376) for the treatment of pulmonary infections in patients with cystic fibrosis (CF). Aeroquin is Mpxe's proprietary aerosol formulation of levofloxacin that has been optimized for aerosol delivery using an optimized Investigational eFlow Nebulizer System.

<http://www.medicalnewstoday.com/articles/213303.php>

### **MEDICATIONS AND TREATMENTS**

**Eradication of *Pseudomonas aeruginosa* in an adult patient with cystic fibrosis.** Don Hayes Jr., David J. Feola, Brian S. Murphy, Robert J. Kuhn and George A. Davis. American Journal of Health-System Pharmacy, 02/15/2011 68:319-322

The administration of continuous-infusion cefepime and high-dose, extended-interval tobramycin led to

the successful eradication of *P. aeruginosa* in an adult patient with CF.

<http://tinyurl.com/4r3vhkz>

**Higher Tobramycin concentration and vibrating mesh technology can shorten antibiotic treatment time in cystic fibrosis.** Allan L. Coates MDCM, Oliver Denk PhD, Kitty Leung BSc, Nancy Ribeiro BSc, Jeffrey Chan BSc, Maria Green RTNM, Sean Martin BSc, Martin Charron MD, Michael Edwardes PhD, Manfred Keller PhD. Pediatric Pulmonology. Article first published online: 30 DEC 2010

Results demonstrate the possibility of delivering equivalent levels of tobramycin much faster into the lungs of CF patients when using eFlow®, a very efficient electronic nebulizer.

<http://tinyurl.com/6ybumsu>

**Lung deposition of inhaled**

**tobramycin with eFlow rapid/LC Plus jet nebuliser in healthy and cystic fibrosis subjects.** Warren Lenney, Frank Edenborough, Pearl Kho, John M. Kovarik. Journal of Cystic Fibrosis. Volume 10, Issue 1, Pages 9-14 (January 2011)

Reducing nebulisation times for tobramycin solution for inhalation in cystic fibrosis (CF) may improve compliance. eFlow rapid reduces the nebulisation time of tobramycin and can potentially improve compliance in patients with CF.

<http://tinyurl.com/4rhzzaz>

**Safety, efficacy and convenience of tobramycin inhalation powder in cystic fibrosis patients:** The EAGER trial. Michael W. Konstan, Patrick A. Flume, Matthias Kappler, Raphaël Chiron, Mark Higgins, Florian Brockhaus, Jie Zhang,

*Continued on page 32*

## **USACFA Director Is Featured Speaker**

**A**ndrea Eisenman, USACFA Director and Executive Editor/Webmaster, will be the featured speaker at The Hope For Breath Foundation's "4th Annual Fundraising Dinner and Chinese Auction" which will be held on June 3, 2011, at Vina de Villa in Medford, NY.

The Hope For Breath Foundation is a 501(c)(3) nonprofit organization that was started by sisters, Christina Tsakonas-Kaiser and Jennifer Tsakonis-Goodale, both of whom had CF. Christina died in 2008, while awaiting a second lung transplant. Jennifer died nine months later. We,

the current members of the Hope For Breath Foundation, are close family and friends of the sisters. As volunteers, our goal is to continue their dreams and to be able to help people like them who have illnesses such as they had.

We help provide financial aid to pre- and post-lung transplant patients who have cystic fibrosis, for medical necessities and/or living expenses with monies raised through fundraising efforts and donations. To make a donation or if you are interested in attending the event, please contact us for more information: The



Hope For Breath Foundation, PO Box 364, Holtsville, NY 11742.  
[hopeforbreath@aol.com](mailto:hopeforbreath@aol.com)

"Applications for candidates to receive a monetary grant are available on our website. Please visit [www.hopeforbreath.org](http://www.hopeforbreath.org) for details. Cystic fibrosis lung transplant patients are encouraged to apply."

***The Hope For Breath Foundation...Improving Lives...One Breath at a Time***

Gerhild Angyalosi, Ellie He, David E. Geller. *Journal of Cystic Fibrosis*. Volume 10, Issue 1, Pages 54-61 (January 2011)

A light-porous-particle, dry-powder formulation of tobramycin was developed, using PulmoSphere technology, to improve airway delivery efficiency, substantially reduce delivery time, and improve patient convenience and satisfaction. Tobramycin inhalation powder (TIP™) has a safety and efficacy profile comparable with TIS, and offers a far more convenient treatment option for pseudomonas lung infection in CF.

<http://tinyurl.com/5v2c9nu>

**Twice vs three-times daily antibiotics in the treatment of pulmonary exacerbations of cystic fibrosis.** D. Adeboyeke, A.L Jones, M.E. Hodson. *Journal of Cystic Fibrosis*. Volume 10, Issue 1, Pages 25-30 (January 2011)

This study confirms that twice daily dosing of both tobramycin and ceftazidime is safe and effective and may be considered more convenient than the current dosing schedules.

<http://tinyurl.com/5tdr67p>

## **BONE DISEASE**

**Bone disease in cystic fibrosis: What's new?** Javier RM, Jacquot J; *Joint Bone Spine* (Jan 2011)

The survival gains achieved in CF patients over the last 30 years have led to the emergence of delayed complications, one of which is bone disease. The fracture risk is increased from late adolescence onward. Vertebral fractures have an estimated prevalence of 14% among CF patients and can cause severe respiratory complications. Bone mineral density (BMD) is below the age-specific range. Studies have shown increased bone resorption, most notably during infectious episodes, and disturbances in bone formation. The numerous pathophysiological

mechanisms that contribute to diminish bone strength in CF patients include exocrine pancreatic failure with malabsorption, protein-calorie malnutrition, inflammation related to recurrent infection, and deficiencies in vitamins D and K. In addition, many recent studies support a role for abnormal CFTR function in the osteoblast dysfunction seen in CF. Appropriate diagnostic and therapeutic management of osteoporosis in CF patients is crucial.

<http://tinyurl.com/6w2dohyy>

## **LUNG TRANSPLANT**

**Outcomes of patients with cystic fibrosis undergoing lung transplantation with and without cystic fibrosis-associated liver cirrhosis.** E.F. Nash, C. Volling, C.A. Gutierrez, E. Tullis, A. Coonar, K. McRae, S. Keshavjee, L.G. Singer, P.R. Durie, C. Chaparro. *Clinical Transplantation*. Article first published online: 28 JAN 2011

This study provides evidence that cystic fibrosis patients with liver cirrhosis caused by cystic fibrosis-associated liver disease can safely be considered for sole lung transplantation provided there is no evidence of significant hepatocellular dysfunction with decompensated cirrhosis or hepatic synthetic failure.

<http://tinyurl.com/5r96zkj>

**Risk factors for development of new-onset diabetes mellitus after transplant in adult lung transplant recipients.** Xiaoyi Ye, Hung-Tien Kuo, Marcelo Santos Sampaio, Yan Jiang, Suphamai Bunnapradist. *Clinical Transplantation*. Article first published online: 22 DEC 2010

Cystic fibrosis is a strong risk factor for development of new-onset diabetes after lung transplant.

<http://tinyurl.com/24hz949>

## **ABPA**

**Sequential Bronchoscopy in the**

**Management of Lobar Atelectasis Secondary to Allergic Bronchopulmonary Aspergillosis.** Whitaker, Paul MB ChB; Brownlee, Keith MB ChB; Lee, Tim PhD; Conway, Steve MBBS; Etherington, Christine MB ChB; Peckham, Daniel DM. *Journal of Bronchology & Interventional Pulmonology*. January 2011 - Volume 18 - Issue 1 - p 57-60

Lobar atelectasis (lobar collapse) is a common complication in patients with cystic fibrosis. Failure to reexpand the lung is associated with poorer outcomes. The authors conclude that sequential bronchoscopy, with instillation of recombinant human DNase, in patients who fail to show reexpansion of the lung is effective and should be considered as part of standard medical management.

<http://tinyurl.com/4hy8zr5>

## **PANCREATITIS**

**Type of CFTR Mutation Determines Risk of Pancreatitis in Patients With Cystic Fibrosis.** Chee Y. Ooi, Ruslan Dorfman, Marco Cipolli, Tanja Gonska, Carlo Castellani, Katherine Keenan, Steven D. Freedman, Julian Zielenski, Yves Berthiaume, Mary Corey, Susanne Schibli, Elizabeth Tullis, Peter R. Durie. *Gastroenterology*. Volume 140, Issue 1, Pages 153-161, January 2011

Specific CFTR genotypes are significantly associated with pancreatitis. Patients with genotypes associated with mild phenotypic effects have a greater risk of developing pancreatitis than patients with genotypes associated with moderate-severe phenotypes. This observation provides further insight into the complex pathogenesis of pancreatitis.

<http://tinyurl.com/4rkt dxn> ▲

*Laura is 63 and has CF. She is a Director of USACFA and the President. Her contact information is on page 2.*

# Abbott Offers CFCareForward Scholarships

For nearly 25 years, Abbott has offered a variety of resources to support the cystic fibrosis (CF) community through the CFCareForward program. Recognizing the financial burdens that exist for many CF families, the CFCareForward Scholarship was developed to honor young adults with CF as they pursue goals of higher education and beyond.

Scholarships are awarded based on an applicant's creativity, academic excellence, community involvement and ability to serve as a positive role model for the CF community. For more information, visit [www.CFCareForwardScholarship.com](http://www.CFCareForwardScholarship.com).

## 2011 Quick Facts

- Forty CFCareForward Scholarship recipients will be selected to receive \$2,500 for use during the 2011-2012 academic year.
- The recipients will be given the opportunity to com-

pete for a larger scholarship in one of two categories, based on level of study. Two Thriving Student Scholarship recipients will be selected in 2011 – the Thriving Undergraduate Student and Thriving Graduate Student.

- Both Thriving Student Scholarship recipients will be awarded \$19,000, in celebration of the 19th year of the Scholarship. These awards will be given to the recipient with the most votes in each category after a month of online, text and phone votes from the general public along with a panel of Abbott judges.
- Since 1993, scholarship funds totaling more than \$2,125,000 have been awarded through the CFCareForward program.
- Apply online through May 27, 2011: [www.CFCareForwardScholarship.com/apply](http://www.CFCareForwardScholarship.com/apply).

## Calling All Writers

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

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

Here are a few possible topics for your use: headaches; understanding what you hear; pain(s) in the neck; arm twisting; the case at hand; a breath of fresh air; gut reaction(s); pain in the butt; oh, my aching back; getting hip

to a subject; standing on one's own two legs; at the foot of the problem; toeing the line; my sole responsibility. As you can see, these are humorous suggestions that are meant to give you some ideas. You need not use any of these, but you may, if you wish. For other ideas, check out the Looking Ahead section on page 3. All submission dates for the coming year are posted there.

We ask that all submissions be typewritten. If you want to e-mail your submission, please have it in Microsoft Word or a similar program. You may send your submissions to: [cfoundtable@usacfa.com](mailto:cfoundtable@usacfa.com)

or to  
USACFA  
PO Box 1618  
Gresham, OR 97030-0519.



## *In Memory*

**Dorothy Corwin, 65**  
Jacksonville, FL  
May 21, 2010

**Raymond Corwin, 39**  
Jacksonville, FL  
October 21, 2010

**Dennis Rockford, 55**  
Ottawa, IL  
January 16, 2011

*Immediate family members may send in the names of CF adults who have died within the previous year for inclusion in "In Memory." Please send: name, age, address and date of death.*

**Send to:**

CF Roundtable, PO Box 1618,  
Gresham OR 97030-0519.

**E-mail to:**

cfroundtable@usacfa.org

# Executive Director Position Available for Breathing Room

**B**reathing Room is a cystic fibrosis (CF) specific Arts and Healing organization ([www.thebreathingroom.org](http://www.thebreathingroom.org)) that was founded over 10 years ago. We are an all volunteer, non-profit organization and our keystone project is "Through the Looking Glass: Images of Adults with Cystic Fibrosis". *CF Roundtable* features a Breathing Room image in each issue and we have exhibited at cystic fibrosis conferences since 1996.

- We currently maintain a collection of over 40 photographs and writings, and exhibit the collection at CF conferences and education days throughout the United States.
- The position of Executive Director is a volunteer position and requires a time commitment of 10-20 hours per week.
- We are looking for someone with a strong vision of what the Breathing Room is, the value it brings to the greater cystic fibrosis community and who can carry on the mission of Breathing Room.

- The ideal candidate will have a commitment to the CF community, believe in the concept of Arts and Healing and demonstrate the ability to manage and organize an all-volunteer organization.
- In addition, the person should have experience with fund-raising and be willing to travel throughout the United States.
- Website design interaction, social media skills and professional contacts throughout the cystic fibrosis community are a plus.
- Someone with a personal connection to CF is preferred, but not required.

If you are interested in this position, please send a résumé and letter of interest (e-mail or snail mail) to: [michelle@thebreathingroom.org](mailto:michelle@thebreathingroom.org) or Michelle Compton, 17499 San Franciscan Dr., Castro Valley, CA 94552

***Applications accepted through August 1, 2011.***

# CF ROUNDTABLE SUBSCRIPTION FORM (Please Print Clearly)

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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 .....\$ \_\_\_\_\_
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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 KEEP YOUR SUBSCRIPTION UP TO DATE

**D**o 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  
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If it is time for you to renew your subscription, you should have received a reminder with your newsletter. Please be sure to complete and return that 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.

## IMPORTANT CHANGES

You may have noticed that USACFA and *CF Roundtable* have experienced some changes. There are new officers and board members in our organization. *CF Roundtable* has a different column: "Editor's Notes" rather than "A Word from the President." Also, USACFA has expanded to the point where we have two separate addresses for different purposes. We ask that all correspondence that does not include any money in it be sent to the old PO Box number and that all mail containing money of any kind be sent to the new PO Box.

When sending in a subscription or donation of any amount, send it to: **USACFA, PO BOX 151024, ALEXANDRIA, VA 22315-1024.**

All articles, general inquiries, comments, questions, or praise should be sent to: **USACFA, PO BOX 1618, GRESHAM, OR 97030-0519.**

## 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](mailto: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](mailto:cflegal@cff.org).



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## IMPORTANT RESOURCES

**Partnership for Prescription Assistance:** Phone: 1-888-477-2669 [http://www.pparx.org/prescription\\_assistance\\_programs](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](mailto: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/>