

CF Roundtable

A NEWSLETTER FOR ADULTS WHO HAVE CYSTIC FIBROSIS

WINTER 2012

Our Pets and How They Affect Our Lives

By Jim Chlebda

For better or worse, Cheri and I lived together for a number of years before we finally tied the knot. We started out renting a small house (which we were able to purchase later) in a small West Valley neighborhood in Los Angeles. On occasion we, in turn, rented out rooms to friends in need.

Not only did we have a pet—we had a whole menagerie. Osky, our cat, manned the front porch. Tripper, Diga and Cotati were our three shepherd dogs in the backyard. I had made a large rabbit hutch that stood in the shade of a plum tree next to a shed in the back corner of the yard, where we bred and raised rabbits. Inside the house, we had a variety of birds: Hercules was a grey cockatiel; Ruau, an amazing canary who sang the most light-hearted melodies; rounded off by a pair of brilliant

green Fischer love birds and some red-billed finches. All our friends knew we had a way with critters big and small.

So it was no surprise to get a phone call one afternoon. Some of our bachelor friends had a pad together and were visiting Sharna over the weekend, where we often used to gather for parties. Seems they were leaving one of those gatherings in the wee hours and happened upon a cat stalking some kind of owl in the middle of the street down the hill from Sharna's place. They had rescued it and promptly brought it back to their apartment. Only problem was, the owl got a little restless and they had no idea what to feed it. On top of that, it seemed quite ill mannered, and proceeded to trash their apartment in a fairly short period of time.

I had to laugh at their predicament, after listening to Larry describe the unanticipated ordeal they'd gotten themselves into. The guys



DARK STAR AND JAMES CHLEBDA.

brought it over as fast as they could. Cheri and I had suddenly acquired an unexpected new roommate.

Upon initial examination as we were getting acquainted with what was definitely a barn owl, we saw that the cat left a nasty scratch across the owl's beak. After gently cleaning and swabbing a few times with hydrogen peroxide on a cotton swab, it

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EDITOR'S NOTES

By now, I think we all have had a taste of winter weather. I hope it has not been too bad where you are.

In this issue, our Focus topic is: "Our Pets And How They Affect Our Lives." We have many articles that deal with this topic. I hope you already have read **Jim Chlebeda's** article which starts on the front cover. His story of Dark Star is quite interesting. **Isa Stenzel Byrnes** transcribed a message from her dog, Rupie, in *Spirit Medicine*. In *Speeding Past 50*, **Kathy Russell** writes of several pets and how one is out to get her. **Jennifer Hale** explains how her dog, Sophie, changed her life, in *Coughing With A Smile*. **Anne Williman, Susan LeBoeuf, Nicole Matthews, Laura Tillman** and **Andrea Eisenman** all tell of their special relationships with their pets and how they have enriched their people's lives. *Through The Looking Glass* contains an image and prose from **Catharine Martinet** about her dog, Augie.

Beth Sufian uses *Ask the Attorney* to suggest that we need to be realistic about our CF and how it might place some limits in our way. She suggests that people who have CF can follow their dreams, within reason.

On page 18, be sure to read a review of "You Cannot Fail - You Are The Hero Of Your Own Story", written by **Jerry Cahill**. This book can give hope to many people.

On the same page, be sure to check out the "Save the Dates" notice about the CFRI conference and retreat.

Another piece that might have some information that will help you is the Airline Travel Information on page 25. This possibly will answer some questions you may have had about air travel with CF.

Andrew Golubic is in *The Spotlight*, which is written by **Jeanie Hanley** and **Andrea Eisenman**. Andrew tells of his work as an actor and a food server.

In *Wellness*, **Julie Desch** talks of the importance of 'motivation' when using exercise to stay in shape. She gives us some of the benefits of exercise. She also tells us why exercise is so important to our well-being.

We say good bye to a longtime friend on page 13. **Mike Mittelstead** has been a guardian angel to USACFA since we began publishing *CF Roundtable* in 1990 and he is retiring. Thanks for all the years of help, Mike. We'll miss you.

Check your mailing label on the envelope that brought this newsletter to you. If you have a date after your name, you are okay. If it says, "COMP COPY", it's time for you to renew your subscription. Go to page 31 for a subscription form. Complete it and send it to us.

Until next time, stay healthy and happy.

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



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

Cara Brahm

Lebanon, KY

35 on September 10, 2011

Charles Cherry

Oak Harbor, OH

65 on November 11, 2011

Christopher Dopher

Brooklyn, NY

40 on September 17, 2011

Edward Fleischman

Plainview, NY

70 on December 24, 2011

Wedding

Susan & Mark Vitale

Kirtland, OH

42 years on August 2, 2011

Transplant

Valerie Vandervort, 39

Claremore, OK

Bilateral lungs

10 years on October 4, 2011

NEW BEGINNINGS

Wedding

Maggie Sheehan &

Thomas Williamson

Chicago, IL

Married September 15, 2011

Transplant

Charles Cherry, 64

Oak Harbor, OH

Bilateral lungs

September 28, 2011

Mike Darrar, 45

Post Falls, ID

Bilateral lungs

May 3, 2011

LOOKING AHEAD

Please consider contributing to *CF Roundtable* by sharing some of the experiences of your life in writing. Read the Focus topics listed below and see if there are topics you might like writing about. In addition, humorous stories, articles on basic life experiences, short stories, art work, cartoons, and poetry would be greatly appreciated. We require that all submissions be original and unpublished. With your submission, please include a photo of yourself (as recent as possible) as well as your name, address and telephone number. Photos will be returned. Send all submissions to: **CF Roundtable, PO Box 1618, Gresham, OR 97030-0519.** Or E-mail to: **cfroundtable@usacfa.org**

Winter (current) 2012: Our Pets And How They Affect Our Lives.

Spring (May) 2012: Are You An Optimist or A Pessimist? (Submissions due March 15, 2012.) Do you see the glass as partly full or partly empty? Do you start each day with a smile or a moan? How does that way of thinking affect your health, your job, family etc.? Whether you are an optimist or pessimist, were you always that way or did you become that way? Does CF play a part in that?

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

Autumn (November) 2012: Organ Transplant - has it met my expectations? (Submissions due September 15, 2012.)



ASK THE ATTORNEY

Being Realistic About One's CF

By Beth Sufian, Esq.

By the time you read this column, 2012 will have arrived and with it a new year with new challenges. Many in the general public make New Year's resolutions regarding weight loss. Many people with CF are eating holiday sweets in an attempt to gain weight (or maybe that is just what I am doing). Others with CF are fighting winter colds or respiratory infections that have resulted in hospitalization or the use of home IVs. It seems that this is a good time to discuss issues related to expectations and plans for the future. One of my New Year's resolutions is to have realistic expectations for myself and to factor in CF when making plans in 2012.

Based on discussions with callers to the CF Legal Information Hotline in the past six months, it seems that many people with CF could make the same New Year's resolutions. Engaging in honest discussions with your CF healthcare team about expectations and future plans is one way to help meet this resolution.

I feel fortunate to have a CF physician who tells me her honest opinion when I ask for her input. Sometimes some of her patients tell me she is too honest with them about their health. I don't think someone can be too honest with adults about their health. I think she is being a good doctor by providing her patients with information about their health, which can help them plan for the future. A person who wants a doctor to sugar-coat the truth is asking for trouble.

When I was sick and still dreaming about going on a fun trip to visit friends, my doctor explained that going on a trip while sick would not

make me better but would result in my becoming much sicker. Yes, I already knew this, but it helped to hear it from my doctor. Making plans based on inaccurate information about your health does not help you and does not help your health. A doctor who will tell you how to keep yourself healthy and informs you when you are making bad choices regarding your health is a great doctor. While you may not always like what you hear, it is better to hear the truth than to take action based on an incorrect belief that you can do anything. As I tell my 11-year-old daughter, no one can do everything they want to do, at all times in their lives. Sometimes things do not work out as you planned. Sometimes you need to change your plans to accommodate your health. Accepting your limitations and planning for the future while considering your health can have a positive impact on your health.

Recently we have received many calls at the CF Legal Information Hotline from adults with CF who

need to stop work due to declining health. These callers have reminded me how important it is for people with CF to make informed decisions about work activity and the pursuit of a career. Many callers recount similar discussions with their CF care teams about career choices. The person with CF is told to "Follow your dream," "Do whatever you want," "The sky is the limit," "Don't let CF stand in the way of having whatever career you want to pursue." While it may seem nice to think that people with CF can do whatever they set their minds to do, it is not always realistic and can result in some unfortunate situations for people with CF.

While no one wants to take dreams away from the dreamer, it is important for people with CF to receive accurate and realistic advice from their healthcare teams about career choices and future plans. The people with CF may not like what they hear but, at the very least, the truth may allow the person to avoid incurring large student loans for a career pursuit that is unrealistic.

There are varying degrees of disease severity among people with CF. What may be an unrealistic career path for one person with CF may be realistic for another person. Therefore, it is important to have honest and frank discussions with your CF care teams to determine what type of work activity is best for you or if it would be better for you to pursue part-time work or volunteer activity and disability benefits, if your health care needs are too time consuming to allow full-time work.

This past year the CF Hotline has received many calls from people with



BETH SUFIAN

CF who either are in nursing school or who are employed as nurses but must stop work due to a decline in health. The callers live in states throughout the country. Many of the callers were told there was no problem with their pursuit of a nursing degree. There are no discussions about issues related to nursing school that can be problematic for some people with CF. Some callers report that their CF healthcare team did advise them against going to nursing school, but the person had always dreamed of being a nurse so the person ignored the advice.

A large part of nursing school is the requirement that nursing students work in different sections in a hospital as part of the nursing school curriculum. These “internships” are not for just a few months but continue throughout the entire nursing school experience. A person with CF may not be able to participate in many of the hospital rotations depending on their culture status.

For example, if a person is culturing MRSA, it is likely the hospital will be able to exclude that person from working with most patients, due to the risk of cross infection to other patients. A person with CF and MRSA is a risk to another person with CF but can also be a risk to other people with other medical conditions. Some hospitals require all employees to submit to a test for MRSA if the employee will have direct contact with patients. If a person with CF has MRSA, the person may not be able to participate in the nursing school hospital rotation requirement making it impossible for the person to complete the required nursing school curriculum.

The Americans with Disabilities Act may require the school to allow the student to have a reasonable accommodation, but if there is no

reasonable accommodation to completing the bulk of the nursing curriculum that revolves around doing in-hospital training, then the person is not qualified for the nursing program. While a person with CF may dream of becoming a nurse it may be impossible to make that dream a reality if the person is culturing MRSA. Or in some cases, the person with CF becomes a nurse but finds that daily contact with people who are sick results in being sick a lot. Nursing may not be the right career if it causes a person's health to decline.

The United States Supreme Court has ruled that employers can refuse to employ a person with a disability if that person is a risk to themselves or others in the job. If a person with MRSA is a risk to the patients in the hospital, then the person can legally be refused a job and likewise a nursing school may refuse to allow students with CF and MRSA to complete their nursing school course work in the hospital. Often I speak to callers who have taken out large school loans to pursue a nursing career only to find that they will not be able to complete the nursing school requirements or they have trouble staying healthy while working as a nurse.

Adults with CF should seek out accurate information about any careers they wish to pursue and ask their CF healthcare team for advice regarding career choices. The person with CF will have to make his/her own decision, but it is helpful if that decision is made with accurate information about issues that may arise and the limitations of the law and the protections of the Americans with Disabilities Act.

If a person knows the issues he/she may face while pursuing a career but still decides to pursue the career

that is his or her choice. People may choose a different career path if they understand issues they may face in a certain career. Information about a future career may be unpleasant or disappointing but it should not be ignored.

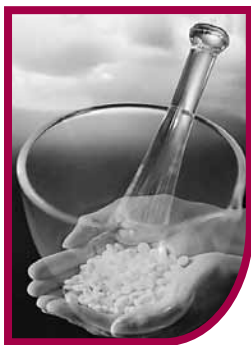
Unlike people without CF, many people with CF must spend hours each day doing medical treatments. In addition, people with CF are at greater risk of getting sick if they work around others who are sick, for example in a hospital setting. Recognition of the need to have time to perform daily medical treatments and avoid people who are sick should play a part in determining a career path or work opportunities.

People with CF should choose the right career path for them. For some, full-time work will be the right path. For others, part-time work or volunteer work and time to take care of themselves may be the right path.

Hopefully, the ideas in this column have raised some issues you may not have thought of and will help you come up with some good new year's resolutions for yourself that will help you have a happy and healthy 2012.

Do you have questions about the laws that protect you in the workplace or questions about rules related to Social Security benefits? Contact the CF Legal Information Hotline at 1-800-622-0385. The Hotline is sponsored by a grant from the CF Foundation and is the only CF resource staffed by attorneys. ▲

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



SPIRIT MEDICINE

A Love Letter from Rupie Giles

Transcribed by Isa Stenzel Byrnes

To my Mommy, Isa:

The time has come for me to write a letter to you. I haven't used words all my life, but you always understand me. And as you know, I am getting older and weaker. I can't leave you without sharing some divine messages I've carried with me all these years. Some of them you already know. But there's more.

Remember when I flunked the obedience test to be a therapy dog?

They wanted me to lie down. I'm a basset hound; I won't lie down if I don't want to! I want to tell you that I don't need a yellow cape on my back for people to know I'm a therapy dog or a guide dog. I want to tell you a secret... I *have* healed you; I *have* guided you, as directed.

I have come into your life, sent by a greater power. You arrived at the shelter to take me on a walk at just the right time. Our reunion was planned. God gave me a job, and I'm so grateful.

I want you to know that before I came to you, I was infused with multiple loadings of loving spirits. Each of your friends—who left this world because of cystic fibrosis, came to me—Karen, Katie, Liz, Bob, Keegan, Tony, Hayley, and the list goes on and on. Each one visited me and gave me a message. I was to convey to you the immense love that they shared with you at one point in time. I was asked to express that love to you each time I

gazed into your eyes, and each time I was in your arms. And that's what I tried to do. You knew, didn't you? I wasn't just myself; I was a collection of many forms of love.

Remember, 'God' is 'dog' spelled backwards! So, I represent God's love to you. My job was to express it all to you, by showing you in every way, how I could love you. And although you already know this, dog also stands for 'Do Only Good.' That's what I've tried to do for you. Even though I

chewed up your nebulizer once, I hope you've forgiven me and know that I was a restless spirit back when I first came to your home. But my intention was good.

God didn't bless you with children, but he blessed you with many other gifts. To be honest, all of the maternal love that accumulated inside of you since you became a woman was being stored for your perfect match. How lucky I was that I was chosen to be a child for you. You and Daddy have

raised me well and given me a very happy life.

We've shared some unforgettable times. I loved backpacking together in the Sierras, frolicking in the snow, and roaming the local beaches (you know I love to eat seaweed). I loved our hikes through the red-

woods and even just our neighborhood jaunts. I especially loved cuddling with you, when our souls fused and we both transmitted explosive energy between us. I'll never forget how I made you laugh, like when I play with my food, climb the furniture or when I get neurotic bursts of energy and run around the house. You say I am silly, but I am just being myself.

Despite all these great times, my favorite memories with you were when we'd sing together. You'd pick up this octopus-like thing, and blow into it. (I think you called it 'bagpipes.') You made a loud howl that made me shiver at first, but then something stirred deep within me. And as you continued to howl, I'd

"I'm not afraid of dying. You humans worry too much. I don't count my days. I just wake up and wag my tail with happiness when you are here."



ISA STENZEL BYRNES

howl alongside you, and I knew we were a pack. We belonged together.

Sometimes I have nightmares that make me twitch in my sleep. I'm often brought back to the worst days of my life, when I was roaming the streets of Central California. My master hurt me and I ran away. I was completely alone. I was scared and hungry. My head hung low. Then a nice man found me, and fed me. Before he dropped me off at the shelter, I looked deep into his eyes. He emanated a magical glow, which I felt. Yet, I was surrounded by an aura of sadness, because his eyes seemed to foretell a tragic but beautiful end to his life soon. And I felt a deep conviction that I'd meet him again, in some way.

You've healed me, Isa, because when I came to you my body was hurt and tired. When I found you, I let out a great whimper of relief; my spirit was soothed. I knew I was home.

God gave you a troublesome illness. At first, your coughing scared me, but I got used to it. I knew you were sick because of all the tubing on your face and all over the house. That's why I didn't lick you. But I wanted to, because I wanted to heal you.

After you adopted me, I remember when you were gone for a long time. Daddy told me you had a transplant, and you'd stopped coughing. Then one day he brought you home from the hospital. I rushed to you, yelping and wiggling. Then I sniffed. You smelled different. Hairs stood up on my back. I sensed another man. As if a long-lost friend came back to me, I felt him. I knew this was the good, loving man who saved me. He did something very kind to you too. Now, he was part of you. And so, over the years, I didn't just love you, but I loved him too, for letting me be with you for nearly nine more years. If your life had ended when I was just a puppy

... oh, it's too painful to think about. I would have curled up in a ball and died of a broken heart.

I can't breathe very well these days. I know you understand what it's like. I make loud snorting noises just to get the air in. The tumor in my nose hurts, and I don't feel well. You whisper to me that you wish I could have a nose transplant, and we could do rehab together again, like we did after your transplant. But you know, there aren't any heroic treatments for me; if there were, they'd just prolong my suffering. I want my dignity to go naturally. But it's hard. I don't know how much longer I can hang in there. All I know for sure is that I want to hold on to you because our love is intense. So I'll do my best.

I'm doing what you once did, when you thought your life was coming to an end. You reviewed all the good times you've had, and felt no regrets. That's what I'm doing these days, when I'm resting on the couch. You think I'm sleeping, but in fact my mind is traveling to the lake, to when I chased a chipmunk while we were camping.

You sometimes tell me you're sorry, that there's nothing you can do for me. But you can. You can be with me. You can hold me. You can feed me pills in cheese that take the pain away. You can wipe my bloody nose. You can give me tasty canned food and take me on walks. I want to see the ocean, run through a meadow, chase a few more squirrels, and gaze out at a grand vista point. Take me to those places before it's too late.

I'm not afraid of dying. You humans worry too much. I don't count my days. I just wake up and wag my tail with happiness when you are here. That's what God wants me to do. He doesn't want anyone to fear dying. Death is just like chasing squirrels. It

comes suddenly and there's a mysterious burst of energy. Then, I will be somewhere else.

When you pet me, you often say sadly, "Rupie Giles, nothing gold can stay." That is the Universal truth. All living things come and go. That is how life is connected. God graced us with coming into being, and that's a miracle. So maybe you can see that we are also graced to move out of this world, into a better place without ticks, poison oak, baths or tumors. And I hope what you hope—that dogs can enter Heaven, so we are granted the chance to embrace each other again someday.

And when it's time, I want just the same as what you want. I just want to be held tightly by you, Daddy and Auntie Ana. I want to be warm, soft and comfy. I want you to stroke my ears, whisper sweet nothings to me, and caress my paws. I will float away from this world full of bliss. It's okay; don't cry too much. We had a great life together. My time is fixed. I cannot fight it, wishing it were longer. It just is. I will return to my Creator, and my love for you will once again join the love of all of your long-gone CF friends. God does amazing things with love. This ball of light will spin and grow, until the next dog or human is infused with this love. He or she will come into your life, and you will feel it. The connection continues. I will be there.

Know that I love you like God loves you. Our bond is sacred and transcendent. I have tried to heal you like God heals you. And I thank you for embracing my spiritual medicine. ▲

Rupie Giles Byrnes is 10 years old and lives in Redwood City, California with her daddy, Andrew, and mommy, Isa Stenzel Byrnes, who has CF and is eight years post-transplant.



SPEEDING PAST 50...

Dogs, Fish And A Slithery, Silver Snake

By Kathy Russell

I have had pets most of my life. Most of them have been dogs, but there were other types too. I was very young when I got my first dog. He was a black and white poodle-terrier mix. His hair was very curly. He weighed about 20 pounds. He was the most loving and gentle dog that anyone could have. He protected me and was protective of other children as well.

He must have had some shepherd in him, because he loved to herd the neighbors' sheep back home every time that they got into our yard. He was so adept at getting them rounded up and headed back home. Later he did that with kids, when they got too rambunctious. What a great dog!

I also had goldfish and black fantails. They were such a pleasure to watch as they swam around and interacted with each other. Their bowl was a "new-fangled" type that had a large, clear loop handle that they could swim through. They appeared to enjoy the swim up and over. I certainly enjoyed watching them. They had me so well trained that when they were hungry, they would go to the surface of the water and smack their lips. It was loud enough that I could hear it from a few feet away. I would feed them and they would start their swimming routine, once again. They lived much longer than such fish usually do. I guess they just had an easy life and were lucky enough to stay healthy.

When I was in school, I raised rabbits and had laying hens. I know that the conventional wisdom is that one should not make pets of "farm" animals, but I never was conventional. I had a large, white buck rabbit that had the run of the yard. He would

hop out of his hutch to go find the best clover and other tidbits. When he was full or just tired, he would hop back up into his hutch and be quite content. He was the only rabbit that had that kind of freedom. The others were kept in their hutches and I just hand fed and petted them there.

The chickens were allowed to roam free. They never strayed far from their enclosure. They were rather "chicken" about getting out. They scared easily.

At the same time that I had rabbits and hens, I also had a grey Toulouse goose. The goose's name was Matthew, until he layed an egg and became Matilda! She eventually went to live with more geese.

My original dog was killed, when I was in my mid-teens. I did have another dog after that, but didn't take it with me when I went off to school. My folks kept that dog for the rest of its life.

After Paul and I married, we decided that we didn't want any pets.

We both were working odd shifts and didn't think it would be fair to a pet to have it be alone so much. Also, we didn't want to be encumbered if we might want to travel. That worked for a few years, until we were given a little terrier pup. She had no manners and was a real character. She fit right in with us. She lived with us until she was poisoned. We missed her for a long time. We spent the next few years without any pets.

Then we bought our current home, which sits on a little more than two acres. We certainly had room for pets. We ended up with three dogs -- a little black and white terrier-Chihuahua momma, a mostly black terrier-poodle daddy and one of their sons that looked like a miniature Doberman pinscher. We got the momma when she was about eight weeks old. Her person had died from a brain aneurism and she needed new people. She was so little that she could sit in Paul's hand. She was very quiet and a little timid. Paul taught her to bark. (Thanks a lot!) We got the daddy about a year later, when he was six weeks old. The son was born about a year after that.

Each of our dogs had a distinct personality. Enu, the momma, was a sweet and loving momma that weighed about seven pounds. Oh-No, the eleven pound daddy, was a bit gruff and grumpy, but he was a terrific cuddler. Harpo, the son, was mostly quiet and was my protector. Anyone would take a real chance of getting eaten alive (by a ten pound dervish) if they threatened me in any way. Oh-No lived to 14, Enu to 15 and Harpo to 18.

During those years, I also had an aquarium with angel fish. I found that



KATHY RUSSELL

when life was getting to be too much for me, I could turn off all the lights except the aquarium, and just watch those beautiful fish. It was very soothing to my soul and mind. I always have been a person who likes to be alone and watching those fish was a great way to blot out the rest of the world and just relax.

All my pets were such comfort to me, especially when I was feeling poorly. When I would lie down for a nap, each one of the dogs found a favorite spot to snuggle. Enu would snuggle up to my front. Oh-No got behind my back and Harpo would cuddle in the back of my knees. If I started to cough, they all would reposition themselves to shut me up and get all of us back to sleep.

When Paul was working long hours on the evening shift, “the terrible threesome” kept me company and made sure that I got up and out of the house. They communicated with me and seemed to understand how I felt and if I wanted to play or be left alone. I never was lonely with them around. Their antics were great for my airway clearance too. I always would start coughing from laughing at their games and playing.

These dogs loved fruits and vegetables. We always had a huge garden, at that time, and they loved to be in the garden. When I would be down in a row, weeding, I might move some grass or a plant and find a bright-eyed, little scamp looking at me through the leaves. Ears would be up and tongue out, with tail wagging at ninety miles an hour, as if to say, “Wanna play?!” I never could keep a straight face and would end up rolling in the dirt laughing with them. And when one of them (or all of them) would pick green beans or cherry tomatoes from the vines, for a fresh snack, it really tickled me.

I know that many physicians say that people who have CF shouldn’t have pets. I respectfully disagree. I have been around animals all of my life. While we had the three dogs, we also raised chickens, turkeys and pigs.

We had as many as 800 chickens at one time. I cleaned and refilled waterers and feeders and cleaned out coops and pens, making sure that they had fresh bedding. We raised the poultry so that we could have antibiotic- and hormone-free meat. At that time, such poultry was not easily available on the open market.

Although the pigs, chickens and turkeys were not technically pets, they were animals who relied on me and needed me to ensure their well-being. I needed to be in good shape to deal with all of their needs. I raised such animals for several years, other than the pigs – they were just a two-time experiment - until I could buy natural chickens and turkeys in stores.

As our dogs aged and arthritis and other maladies took their toll, it was our turn to offer comfort to them. We helped them onto and off of the bed and couches, as well as up and down steps. We made sure that they had soft warm comforters to curl up in and to help keep old bones warm. It was the least we could do for them. When the last one died, we decided that we needed to take a break from having pets.

Several years elapsed and then the slithery, silver snake entered our lives. This snake lives in the house and tries to wrap around our feet to trip us up. So far, it has succeeded in tripping me once. I went down so hard on one knee that I thought I had broken something. Fortunately, it was just a bad bruise that hurt for about a year. I was able to walk and didn’t need any treatment for it.

You might be wondering why I would have such a dangerous and sneaky thing around. It’s one of those things that we must sometimes endure. My snake is my oxygen tubing and it is determined to “get” me. I have about 50 feet of hose that follows me around in the house. It allows me to move all over without having to carry a small container of oxygen. The concentrator is located in an unused bedroom so that barely hear it.

Paul always can find me, by following the hose. We both grumble about that blankety-blank hose, but we are happy that there is something that can allow me to live a fairly normal life. Without the supplemental oxygen, I would not be a normally functioning adult. I guess that this “pet” is here to stay. At least I don’t have to feed, water or walk it!

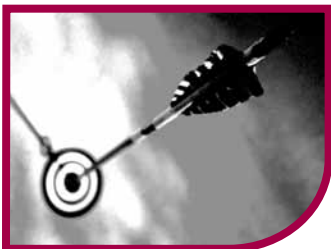
I don’t know if we will ever have another regular pet. I learned, long ago, that I should “never say never”. Maybe we will find a pet that can live with us and bring laughter and friendship into our home. Until then, the slithery, silver snake will be my pet.

By the way, I have received many requests to be someone’s “friend” on Facebook or to “link up” with someone on LinkedIn. I do not use these or other forms of social media. (A couple of years ago, I signed up on Facebook for a one-time-only look at some family photos and I wouldn’t even know how to get there again.) So don’t take it personally, if I don’t respond to your requests on any of these media. I just don’t do it. ▲

Stay healthy and happy.

Kathy

Kathy is 67 and has CF. She is a Director of USACFA and is the Managing Editor of CF Roundtable. Her contact information is on page 2.



FOCUS TOPIC

OUR PETS AND HOW THEY AFFECT OUR LIVES

I Love My Dogs

By Anne Williman

I've always loved dogs. Maybe it's because I'm allergic to cats, so my parents bought me a puppy when I was young. I'd been diagnosed with CF a few years before that, and the doctors told them I wouldn't live to be ten. They should take me home and try to give me a happy life.

Anyway, I named him Petie, and he was so cute and furry. That is, until he grew up to be huge and too much for me to walk on a leash. He even chewed up the head of one of my dolls.

One day I came home from school and couldn't find him. It turned out that my parents had had enough of him, so they'd shipped him off to live on a farm where he'd have room to run. I always regretted that I didn't get to tell him good-bye.

But pretty soon, a new puppy arrived. She was an English springer spaniel that we named Muffin. That dog lived to be very old and I enjoyed her immensely. We even had her bred and had the fun of puppies to raise. Of course, the worst part was selling them.

When Jon and I got married, it didn't take long before we got our own dog, a little black mutt we called Charity. She loved to hug. I'd pick her up, and she'd wrap her back legs around my waist, hook her front paws over my shoulder, and drop her head down on top of her paws.

Charity didn't always exactly live up to her name, like when she bit our little nephew on the lip. When our daughter Amy arrived, Charity ended up going to live at the dog retirement home, aka parents' house.

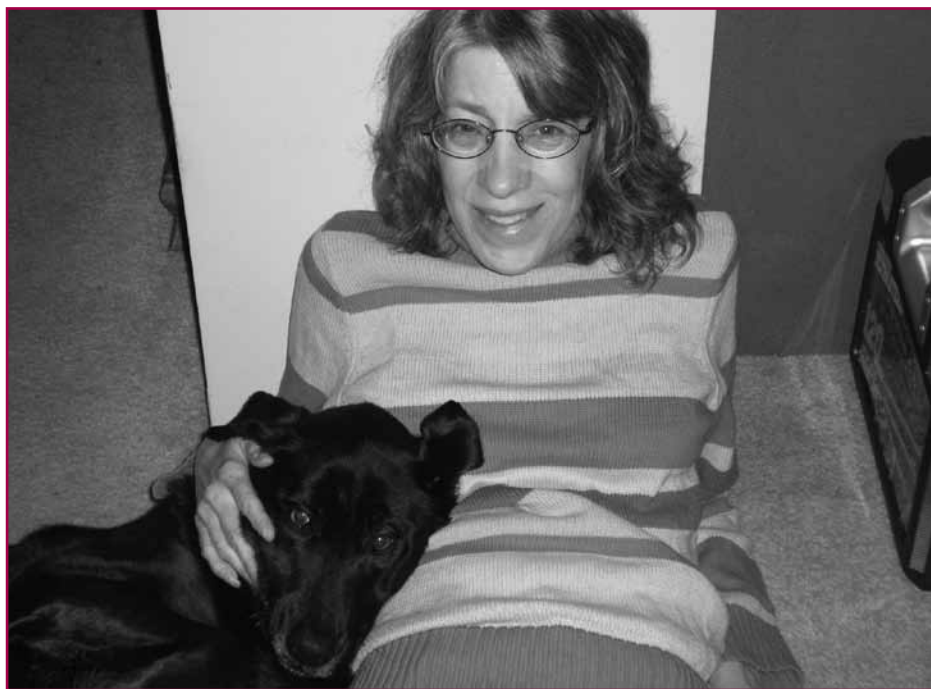
Our other dog at the time, Grace, did better with the new baby, and she

(the dog, not the baby) got to stay. When I picked out Grace's name, I didn't realize that it was also my mother-in-law's middle name. She never said anything, but I got the feeling she didn't take it as a compliment.

In the 37 years we've been mar-

sight of us. But she went on to make a full recovery.

Another of our dogs became our miracle dog after being lost in another part of our state for three months. God answered my prayers and brought her back safely.



ANNE WILLIMAN AND RHEMA.

ried, we've had a total of six dogs, all of which lived to reach their mid-teens. We always kept two at a time, to keep each other company. Since I was working as a free lance writer out of a home office, I was usually around, except for an occasional hospitalization.

We've had some terrible experiences with the dogs, like when one got into rat poison and almost died. She had to have a blood transfusion from the vet's on-site "donor dog" and spent several days in ICU, struggling to live. When we went to visit her, she was so weak that she could only give one quick wag of her tail at the

Of course, as I aged, the CF worsened. That meant more therapy and less strength to do things. But the dogs never seemed to mind, as long as I fed them their dinner every night and let them cuddle up next to me on the bed.

Now our three children are adults and, for the most part, living on their own. Thankfully, our dogs remain with us. Right now, we have two black Lab mixes, Shekinah (meaning God's visible presence) and Rhema (God's personal word). Several years ago, Jon and I got in the habit of walking them most days. They loved it, but more

importantly, it was good for me to get out and do something. I was never much for exercise. We would walk several miles around the neighborhood, and the dogs actually got all excited when they would see me put on my shoes.

When I was in bed, Rhema especially liked to snuggle up next to my legs, and I loved how she kept me warm. She seemed to sense when I wasn't feeling well, and she stuck by me, watching me with her bright brown eyes.

Then in September of 2010, I went into the hospital for surgery. I expected to be home in a week or two, but the day after the surgery, I was transferred to ICU with pneumonia. I ended up spending 30 days there, ten of which were on a ventilator, then another 30 in the hospital until I finally got home.

My family came to visit, but of course, not the dogs. I really missed them! In fact, as I lay there, fighting for my life, I was comforted by the compression boots on my feet. I knew

I wore them to prevent blood clots, but their gentle warm pressure as they inflated somehow reminded me of Rhema, cuddling up to me.

When I was released, I was so weak I couldn't pull myself up out of a chair. I was on oxygen and used a walker. But the dogs didn't seem to mind the "new" me, and Rhema quickly was back beside me in bed.

By spring, I was off oxygen and walking independently. Jon and I decided to resume our walks. For the first month, it was all I could do to get around the block once, and that was possible only after stopping to rest several times. The dogs seemed so pleased to be walking, they didn't appear to mind how short the distance or how slow the pace.

Now after more than a year, we are up to a mile and a half. It's still not as far as we used to go before I got so sick, but I'm slowly progressing. Fortunately, it has been a very mild autumn so we were able to walk far longer than other years. But now that winter is here, I don't like going out into the cold.

We've considered shifting to walking in the mall, but it just doesn't seem right to walk without the dogs. The only thing that might make it agreeable is that we have a six-month-old grandson who also likes walks, as long as you take his stroller.

Yes, my dogs have always been an important part of my life. I admit, when I'm not feeling well, sometimes feeding them or putting them out is a pain. I worry when they get sick or hurt. The few times they've disappeared for a few hours scared me. Finding someone to take care of them when we're gone is sometimes hard, and I'm sure they were pretty neglected the two months I was hospitalized. But all in all, my dogs are worth it, just for the pure love and acceptance they give. No matter how "down" you feel, or how sick your body is, or how upsetting circumstances are, they welcome you with wagging tails and doggy smiles. I love my dogs! ▲

Anne is 58 and has CF. She lives in Middletown, OH.



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My BFFs – Best Friends Forever!

By Susan LeBoeuf

When I was a child growing up, all in my family were strictly DOG people. But since I moved out on my own, way back in the 1970s, I've been a CAT person. My cats, past and present, always have been the best friends I ever could have asked for.

The first cat I owned, right before I was married in 1973, was a beautiful calico whom I named Dizzy. Dizzy was such a funny cat, always running circles around me and constantly chasing her tail. Thus, we named her Dizzy. If I was sick, she was always by my side. She loved me so unconditionally! I was heartbroken when I divorced in 1984 and couldn't take her with me to my new home far away in Illinois.

My next cat came to live with me in 1986. I had recently remarried and my husband, David, re-enlisted in the Army that year. David left for training and I was very lonesome. My sister, who absolutely hates cats, brought me the cutest fur-ball of a kitten inside a box. Instantly, I fell in love with this black bundle of fur, with the big green eyes, that was part Maine coon cat. I named the cat Buddy, but after finding out it was a female she became Buffy.

Buffy was joined by Shadow the following year. David brought him home from a pet store that should have been closed due to sanitation issues. Shadow was a very tiny Tuxedo cat that was losing his hair due to lack of proper nutrition. Buffy immediately became his Mama and taught him how to groom himself. The two of them were always together and followed me everywhere I went. These were my babies!

Buffy and Shadow have a very spe-



SUSAN LEBOEUF WITH HER TWO BFFS, LILY (LEFT) AND TIGGER (RIGHT).

cial place in my heart, because they were with me through my many bouts of being extremely sick. I was in and out of the hospital multiple times through the 1980s and '90s (not yet diagnosed with CF) and whenever I came home they were by my side all of the time. They were the best nursemaids I could ever have asked for, making sure that I was doing okay, sleeping by me and always following me when I was doing things around the house.

Buffy definitely was "my girl." Whenever I would leave the house to go to work or go anywhere she would sit in her perch in the kitchen window and wait for me to come home. The last week that she was alive I had been hospitalized for almost 30 days. She was extremely sick herself at this time and I was very worried about her. My husband even considered sneaking her into the hospital so that I could see her, but we knew that wouldn't have been a good idea.

When I finally returned home from the hospital, Buffy was almost at the end of her life. She had a cardiac disease that was making her very sick. My heart was broken when we ended up having to put her to rest at the age of 16. The loss of my beloved Buffy was very hard for me. I was so sad to say goodbye to my very best friend. Shadow even went into deep mourning for her for a few months.

After Buffy passed away we still had our great friend Shadow. He became very sociable and a loving lap cat. Shadow now ruled the house, without Buffy to boss him around. Shadow lived for another four years until he passed away at the age of 19. Again I was truly heart-broken when we had to say goodbye to that wonderful Tuxedo cat who was always getting into mischief. David and I vowed we would never bring any more cats into our house.

Well, LOL (laughing out loud),

A Guardian Angel Retires



MIKE MITTELSTEAD GIVES ANDREA EISENMAN A TOUR OF METRO PRINTING COMPANY IN SEPTEMBER 2001.

not even a year later we had become owners of, or should I say we were now owned by, two adorable rescue kittens, Tigger and Lily. The “girls” as we refer to them, are a tiger-striped shorthair (Tigger) and a gorgeous gray and white shorthair (Lily). They are not siblings, but they were rescued a month apart from each other so they are bonded like siblings.

Tigger is the most fun cat we have ever owned. She definitely deserves the name Tigger (from Winnie the Pooh) and even bounces around like that character in the Pooh books. She loves to play fetch and she is extremely affectionate with us. She loves us unconditionally and we love her as much.

Lily, on the other hand, is a problem kitty. She was found in a storm drain at the age of four weeks and probably never had nurturing from her mother. Lily is skittish, neurotic and is very nervous around us, yet she absolutely loves Tigger. After being with us three years, Lily is now becoming a little less skittish around us and even sleeps with us when she thinks we are not aware of her presence.

All of my cats have played a big role in how they affect my life. I can't imagine my life without my cats. Do my cats affect CF? Yes, in a very positive way they do. They make me laugh, cry, get mad, and sometimes make me crazy. They have all had very different personalities (who says cats don't have personalities?) and I have loved them all – even with their good and bad traits! All of my cats definitely are my BFF's – my best friends forever! ▲

Susan is 59 and has CF. She lives in Laurel, MD with her husband, David, and their two best buddies, Tigger and Lily. You may contact her at: susanjleboeuf@gmail.com.

In 1990, when USACFA was being organized, we were fortunate enough to meet a wonderful man who has been one of our staunchest helpers and protectors. When we first approached printers to find someone who could help us get our newsletter started, Mike Mittelstead stood head and shoulders above the rest.

We were true novices at creating a newsletter. None of us had any real experience with layout and publishing. Mike and others at Metro Print were very understanding and helpful. Mike always took as much time as we needed to help us get exactly what we wanted. Mike gave us suggestions on how to do things and how to get the best “bang for the buck”. He always has looked out for us.

Mike reads every issue cover-to-cover and frequently finds things that our proofreaders have missed. He has met many of the people involved with the production of *CF Roundtable* and has come to know all of us through the pages of the newsletter.

Mike doesn't have CF, but after so many years of working with us he has learned a lot about CF. He seems to understand what it means to have CF. He has been like a guardian angel to us.

After more than 21 years of overseeing the publication of *CF Roundtable* and almost 22 years of being a mentor to us, Mike is retiring. Although we are happy that he will have more time to pursue his interests, we will miss him terribly. Others at Metro Print will take over the jobs that Mike has done for all these years and, I am sure, they will do a fine job. Still, it won't be the same to not have Mike there. We always knew that we could call and Mike would help us, no matter what the problem was.

So, as Mike prepares for the next portion of his life, we wish him well. “Thank you” seems somehow inadequate for all that he has done for us. We hope that he will stay in touch and that he is blessed with “fair skies and following winds”. ▲



Pets That Help Problems

By Nicole Matthews

Let's start off with how amazing animals can be. They always greet you with a kiss, a paw pat, a tilting head, a jumping hug or a wagging tail, no matter what. They are always happy to see you with unconditional love for you. Now for their bad parts; the main thing is poop, they sometimes stink, shavings, cat litter, messes, and sometimes they are time consuming. Yet, we still love them so much.

I always have loved my animals, even with my CF. I went to a technical school called BOCES and graduated with a Small Animal Care degree. I worked at a high-end kennel for three years.

I always had numerous animals growing up. I started out with just one hamster and a dog; then it grew. In total I have had over 60 hamsters at one time. I had my own little business. I would breed them and exchange hamsters for more hamster supplies. Having these small rodents made me feel like a "normal" kid. It made me care for them as well as myself. Along with the hamsters I had guinea pigs, ferrets, rabbits, cats and, of course, a woman's best friend - dogs.

We had Daisy, a collie mix dog, who lived an amazing life at our home, chasing her tail. Then we got Princess, when I was in sixth grade. She was a Chow-Lab mix that we had to put down, this past October, after 12 wonderful years playing at our home. We now have Daisy, an English bulldog who has quite the attitude and looks. Daisy is not shy of anyone and is always pleased to drool on your pants and kiss your feet and legs.

Coming home after a hard day at work is great! To open the door and get plowed over by a 60 pound bulldog, kisses all over and that little tail

nub wiggling back and forth. She snores quite a bit, but it's cute and acceptable. Animals relieve so much stress; just petting them relieves the tension after a hard day.

I also have my amazing, beautiful cats; Manasseh and Sophie. Manasseh is a long, grey haired, six-year-old cat and Sophie is a Calico, two-year-old kitten. Their attitudes are so different and so fun. Manasseh is my queen cat, and my "guard" cat. If I am wrestling with my sister, Manasseh will attack her or actually growl at her. Sophie is my playful, in-your-face kitten. They know when I am sick; they will not leave my side, and sometimes they

will both lie on the joint that is currently hurting me.

It is said that cats have the power to heal with their purring - I completely believe it. They did not make fun of me, or stop talking to me, when I had blisters all over my face and body from a gluten allergy. They sat in the bathroom with me as I cried over looking like a beast.

My CF does not seem to be affected by my pets. Sometimes the litter or the pet hair is a bother, but a good cleaning seems to help the problem. Having a pet helps relieve the stress and frustration of everyday problems, and most of all, health concerns. They always love you, and will always be there by your side for everything, no matter how horrible you look, how hard you are coughing or how sick you are. They are with you through it all.

Having a pet helps you take better care of yourself. In some way, it makes me a better person - more compassionate, more loving, and more understanding. I have had many pets, and I could sit here and talk about how each one has made me a better person today because of their love and their existence.

Dogs, cats, hamsters, guinea pigs, rabbits, ferrets, parakeets, and fish all have touched my life in a simple way - they make me want to live and care for them, to love them, to be with them. Pets help me strive for life, they make life worth living for, and that's why I think every CF patient should have some sort of animal, to help with our therapy of life. Enjoy your pets, because in reality they truly enjoy you.



**MANASSEH AND
NICOLE MATTHEWS.**

Nicole is 24 and has CF. She lives with her boyfriend, Michael, in Orchard Park, NY.

THROUGH THE LOOKING GLASS

Augie's Clinic



PHOTO BY RAY LOCKETT

She doesn't ask
About the productivity
of my cough
or what meds I'm taking.
My weight is meaningless to her.

But she willingly keeps me company
on those sleepless nights
full of coughing fits.
And extra snacks are just a bonus
to her foraging nature.

She takes no interest
in the results of blood work
or sputum cultures.
Readings from the peak flow
and glucose meters tell her nothing.

For, she already knows
the best way to counteract
unpleasant procedures
a game of tug-o-war,
a belly rub or squeaky toy
makes everything seem a little better.

She has her own methods
for counteracting bad days,
those of shortness of breath,
fatigue and no appetite.

And sometimes all I need
is what she has to offer
the silliness of a jester,
an extra nap on the couch,
soft fur soothing
skin that has felt
too much harshness for one life.

-C.Martinet, 2003

"Through the Looking Glass: Images of Adults with Cystic Fibrosis" and "Caregiver Stories" are projects of Breathing Room, a non-profit organization. Breathing Room hosts these and other projects to facilitate open and candid communication in the CF community, supports the development of a community of adults with CF and provides education and insight for families, caregivers, and medical professionals who impact our lives.

To learn more about us and view more images in the collection, please visit our Website at: <http://www.thebreathingroom.org>

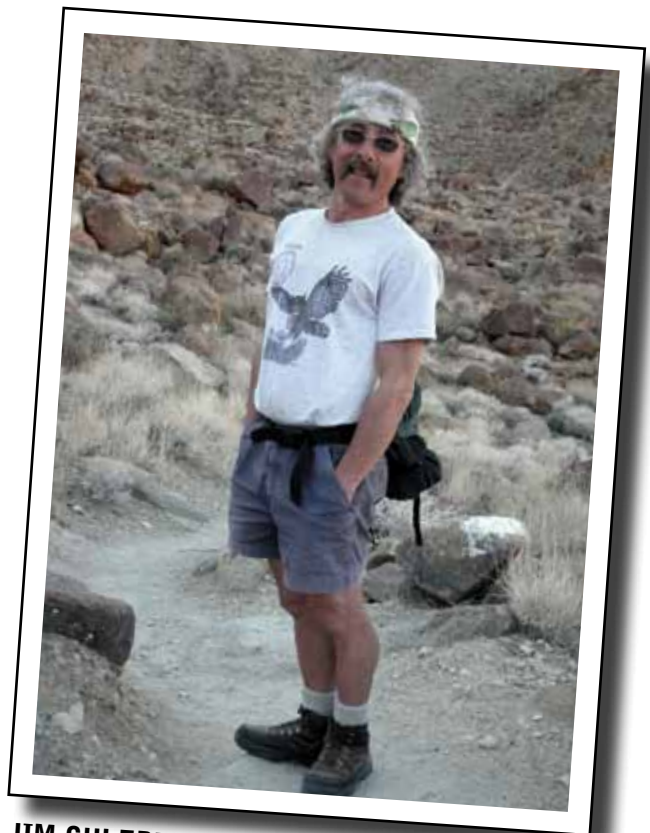
FROM OUR FAMILY PHOTO ALBUM...



ISA STENZEL BYRNES BAG-PIPING WITH RUPIE, SEPT 2011 AT CARSON PASS, SIERRA NEVADA, CA, AT 8500 FT.



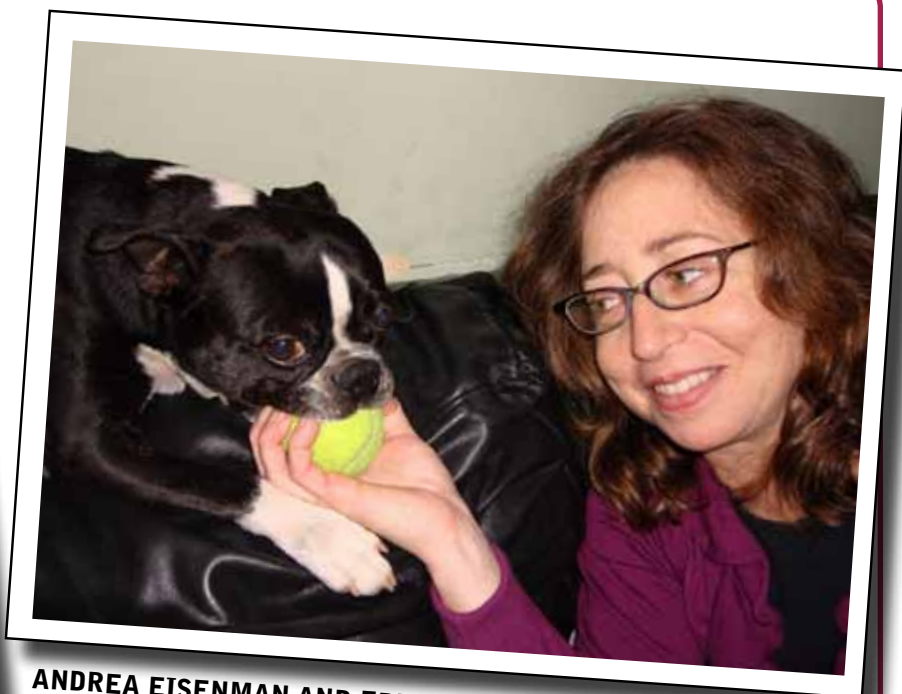
NICOLE MATTHEWS AND DAISY.



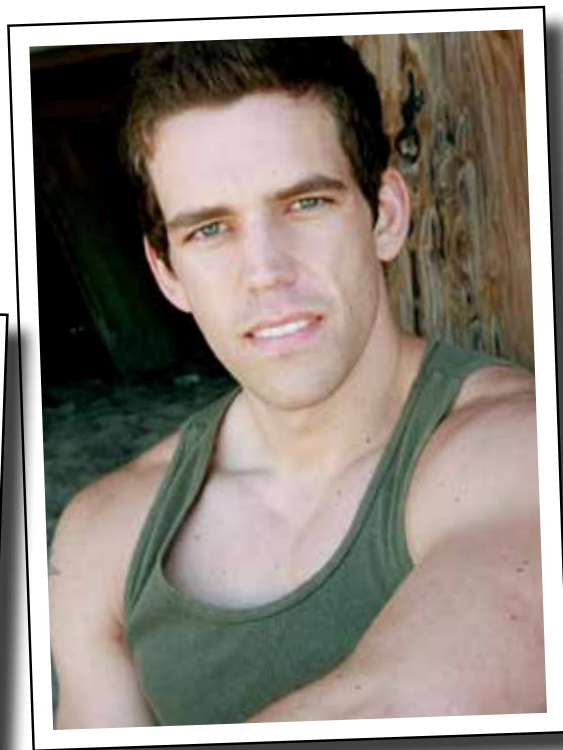
JIM CHLEBDA ON THE 49 PALMS CYN/OASIS TRAIL IN JOSHUA TREE NATIONAL PARK, CA, JANUARY 2011.



JENNIFER HALE AND SOPHIE.



ANDREA EISENMAN AND ERNIE HAVE A BALL.



ANDREW GOLUBIC



SUSAN AND DAVID LEBOEUF, THANKSGIVING IN JAMAICA.



BOOK REVIEW

You Cannot Fail

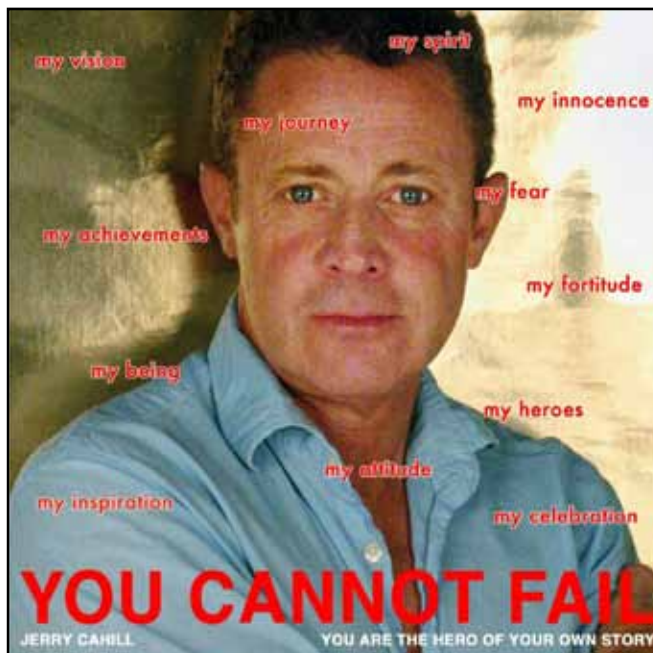
You Are the Hero of Your Own Story

By Jerry Cahill

Book Review by Kathy Russell

"You Cannot Fail" is a book of 40 pages with many color photos. In it Jerry Cahill, who is 55, has CF and is well-known to the CF community, has written of his life and how he strives "every day to make myself, and those closest to me proud, to work toward achieving my goals and to do so with humility and poise." In a series of short essays, he describes his life with CF and how he manages. He explains the methods he uses to handle his hopes and fears and to reach his goals. He includes encouraging quotes from several well-known "thinkers". He makes many suggestions for living life with CF to the fullest.

I am sure that there are many people who have CF, their families and their caregivers, who will find this



book inspirational. For anyone who thinks that a diagnosis of CF means that one cannot succeed at life, this book is a must-read.

This book is the first part of a larger campaign that will include a Web site and merchandise to encourage people with CF and their caregivers, "to accept and embrace the fact that they are, in short, heroes."

Books are available online through the Boomer Esiason Foundation (www.esiason.org) at \$29.95 in small hardcover edition. Autographed copies are \$50. Proceeds from the sales of the books benefit research toward a cure for CF, as well as a new "You Cannot Fail" scholarship. ▲



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healed up quickly without any infection or scarring. I also saw that whoever had it before it was “rescued” by our friends had trimmed its primary wing feathers to prevent it from normal flight. My hope was that eventually the owl would molt out its “old” feathers and grow back full-sized flight feathers, free to leave at some later point in time. We introduced it to our dogs in the backyard, and saw that they understood quickly enough that this bird was just like all the others we had around and was ‘off limits’—no reason to run up to it, chase it, stalk it, or pounce—a satisfactory, trouble-free introduction! Osky, on the other hand, was quite perplexed and freaked out, but we figured the back yard was safer than the front yard for our new friend.

How to keep a barn owl happy? We had an old 50-gallon glass aquarium that I decided to set up sideways with steel-mesh screened compartments and a tight-fitting front screen for breeding our own healthy supply of fresh owl food. This avoided constant trips to the pet store for feeder mice, where too often they were out of stock.

My connection with that owl became an extraordinary, enlightening experience. We clicked right from the start; the owl bonded with me like I was its mate. It was inspiring and gratifying to develop a close tie with this creature.

Being intimately acquainted with cystic fibrosis from an early age, I grew up appreciating and fully embracing the concept of living in the moment. This was deeply reinforced by my relationship with that amazing animal. I named “him” *Dark Star*, as it seemed appropriate for an owl. For variety before I got the ‘mouse farm’ up to full production, I would alternate store-bought mice with smelt, little fish I’d thaw out from the freezer. He’d toss them down like shots, until his half-closed eyes would look over at me as if to say, “OK, I’m full now!”

Dark Star thrived in his new envi-

ronment. At first, we let him roost in the closet of our bedroom where, we assumed, he could sleep in fairly dark surroundings during daylight hours. However, he quickly tuned in to our diurnal habits. He spent his nights sleeping soundly on the wooden clothes rod. Early each morning, he’d fly out, land gently on my bare shoulder in bed and greet me with a chortle and a nuzzle. I’d stretch my arm forward, sliding open the door to let him out to the backyard to poop. Cheri was able to sleep in without any interference from the owl jumping down to our bed.

Dark Star would hop out to the

“My connection with that owl became an extraordinary, enlightening experience.”

patio, up onto a lawn chair, do his business, check on the dogs and head back in, chirping and trilling when he returned to my shoulder, nibbling gently on my exposed ear. We were amazed at his gentle, affectionate personality, and by our observation that he seemed so—intelligent. We did everything we could to make him feel at home. *Dark Star* watched with curiosity as one of us washed dishes; he seemed fascinated and wanted to explore further. So we filled the kitchen sink with an inch or two of clean water and let him hop in for the first of what became one of his favorite evening pastimes.

Often, he would press his fluffy head up against my cheek. I would gently push my fingers through his downy feathers and grasp his little skull (smaller than a golf ball), massaging around his eye sockets and ear canals while he soaked it up, as if in a

trance. I had started off feeding him in the living room, but soon switched out to bringing owl and mouse into the backyard for supper. Imprinting a more natural setting for mealtime seemed sensible. All it took was tossing a mouse gently into the grass—*Dark Star* would swoop down silently from the trellis or clothesline, landing with talons outstretched atop the mouse. Instantly, he would grasp vise-like with both feet, break the mouse’s neck with a sharp tug from his beak, then toss it headfirst down the hatch in one seamless move—lightning-fast and efficient. Barely the tip of a tail still visible and an owl with half-closed eyes meant, *that hit the spot!*

Dark Star was by nature a very gentle creature. With awe I observed his curved ⁵/₈-inch talons, so coordinated when necessary, yet so relaxed when he would land soundly on my shirt sleeved or bare arm or shoulder, never with pressure or breaking the skin. However, if Billy came by, whom *Dark Star* instantly took notice of, he would arch his wings, circle his head back and forth while making a sharp clicking sound with his beak, and aim directly for the top of Billy’s hapless bare head, talons primed for an extra-firm landing! Billy would wince, howl and flail; if *Dark Star* could laugh, I’m sure he did!

He was quite photogenic as well. I was never sure if it was the camera or the person behind the device that was of more interest or concern to our curious little friend.

As time went by we got our closet back, and didn’t have to keep collecting owl pellets (tightly packed plugs of regurgitated fur and bone) from the floor. I had cut a hole above the door of the shed in the corner of the backyard so *Dark Star* might feel more at home outdoors; he could also get used to the night sounds of town. He liked to stand atop the fence on either side

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My Three Sons

By Laura Tillman

In our 36 years of marriage my husband, Lew, and I have had three golden retrievers. All of them were rescue dogs in one way or another. The first, Sam, was our “gifted” child. He taught us everything we ever needed to know about dogs. And thank goodness he knew what he was doing - because we certainly didn’t! Sam taught us to live every day for the moment, to find joy in the little things, and to fight like hell when he was diagnosed with cancer. The lessons we learned from him gave us a foundation for dealing with whatever life threw our way. Little did we know that years down the line, his example would provide a basis for dealing with my diagnosis of CF.

A few years after Sam died, Cooper came into our lives. He was our “special needs” child. Cooper taught us patience, perseverance, and tolerance. At three years old, he had never been inside a house. He wasn’t house broken, feared everything, and didn’t even know how to play with toys. Working with Cooper was like working with a child who had been kept in a closet for the first three years of his life. Everything was new and strange to him. But once we built and gained his trust over many long months, he became a wonderful, loving, contented dog.

Our lives revolved around each other. Cooper thrived on routine and we tried to keep him happy by maintaining the schedule he was used to. Watching Cooper blossom into the carefree dog that he became was extremely fulfilling. However, our pattern was shattered when I was diagnosed with CF. Adjustments had to be made by everyone, including Cooper. And Cooper turned out to be quite the

trooper! No longer could we (especially me) indulge Cooper’s every need and desire. My treatments became paramount and Cooper had to learn to wait until they were completed.

So, Cooper would lie down wherever I was nebulizing my medications and patiently wait for me to finish. When I was first diagnosed, Lew had to do manual percussion on me. Cooper joined us for that, and waited resolutely for us to finish. When the vest came along, it was scary for Cooper, but he soon became used to it and even seemed to enjoy the vibration of it as he dozed on the floor.

When I had to do IV antibiotics, Cooper was there and wouldn’t leave my side, even when the home nurse insisted that he couldn’t be in the room. There was no way that Cooper was going to be forced out of the room away from me. He decided that it was his job to protect me and, no matter what, he was going to be there for me. If the nurse or I managed to drag him out of the room, he returned and curled up under the table where we couldn’t reach him. He became used to the IV pole and didn’t even pay any attention to it when I wheeled it around the house from room to room.

Cooper even came for visits to the hospital, where he jumped onto the bed and wouldn’t budge. Obviously, we had closed door visits or the nurses would have had conniptions seeing him in bed with me! When I took early retirement from my job as a school psychologist, it was very hard on me, but Cooper was by my side every day. We went for long walks all that fall and he provided company and support as I adjusted to my new lifestyle. The walks were good for both of us, and we seemed to flourish.

But, then, Cooper developed health issues, including cancer, for which he received chemotherapy. The chemo caused neuropathy and some other problems, and Cooper spent a lot of time at the vet. When he came home, there were many meds for him to take. As always, Cooper took it all in stride, even learning to swallow his pills when I gave them to him. He would take them from my hand, one at a time, and swallow.

His final summer with us was extremely difficult. Although he was not able to get around much, he was still happy and interested in what was going on around him. A simple treat (even an ice cube) brought him pleasure and he would pick his head up and give a little wag of his tail. He was so appreciative and seemed to sense that anything I did for him was going to help him.

He received an additional diagnosis of Addison’s disease and required subcutaneous fluids; that didn’t seem to faze him as he was used to the IV pole and had seen his share of needles over the years since my diagnosis. All he needed was for me to show him the needle. He would give it a sniff, put his head back down, and just lie there while the fluids dripped into his body.

We took him for acupuncture and spinal adjustments (do you get the idea that we would do anything for our fur-kid?) and, again, he would lie there with the needles in him and just chill out or patiently stand while the vet did the adjustments. Even in his final moments of life, Cooper was serene as long as we were within sight. Cooper taught us much about growing and changing and coping - as he did so with much success.

Cooper’s death was very devastat-

ing for me, as I had been his source of help and comfort, just as he had been mine. It was many years before I could even begin to think about having another dog. And, even then, it was, “If a dog finds us, we’ll know the time is right.”

Well, two years ago, Kirby found us. He was a 14-week-old golden retriever puppy – our first actual “puppy”. Little did we know what we were in for. Talk about exercise. We walked him every two hours during the day, and I followed him around the house constantly to make sure he wasn’t getting into trouble. At least our sleep wasn’t disrupted for long, since he was able to doze through the night within a matter of days.

Kirby is our “problem” child. He’s not laid back and calm like Sam and Cooper had been. Kirby is high energy, full of vim and vigor, curious to a fault, and unable to control his excitement. And most anything is cause for excitement! He’s strong and impul-

sive – not a good combination for me since I’m small and weak.

He even managed to fracture – as well as tear a muscle and cause tendonitis in – my shoulder last May, when he bolted after a dog in a fenced-in yard, as we were walking. Unfortunately, I had his leash around my wrist and couldn’t get it off before I went flying through the air and then came crashing down on my arm; and even then he didn’t stop but continued running – dragging me across someone’s lawn!

Kirby had no idea that I was hurt and showed no remorse for his actions. Unlike his brothers before him, Kirby doesn’t seem to have compassion for others. Instead, he has a mischievous sense of humor and will do whatever it takes to get attention. While he no longer needs constant checking, he stills needs monitoring to make sure he isn’t doing something he shouldn’t. Kirby keeps us entertained and busy throughout our days and evenings.

He’s a source of amusement, frustration, and love.

My three sons. What would my life have been like without the presence of these four-legged beings? My world has been made richer by knowing them. They brought unconditional love, affection, trust and devotion into my life. They were, and have been my closest buddies, always eager to “come along for the ride”, no matter where it took (takes) them. They taught me to wake up each day with a smile, ready and eager to face whatever comes my way. They helped me to slow down and appreciate the little things. They showed me how to face adversity with calmness, perseverance, and dignity. And they continue to bring laughter and delight both in their memories and in the here and now. My three sons. ▲

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

CHLEBDA *continued from page 19*

of the yard, letting out a distinctive, high-pitched shriek. Other barn owls from the neighborhood began replying, and soon were regular night-time visitors. Once, one stood on the fence while Dark Star caught his dinner mouse in the grass below. I was awestruck watching their fleeting connections—and appreciative for the glimpse into this alternative ‘other’ world of these creatures’ brief interactions with each other. It was equally amazing how my presence did not affect the wild owls that came to visit *Dark Star*.

Alas, this saga has a tragic ending. Cheri had a friend who needed a place to stay for a while, but she had a big golden retriever. The dog came with Leta, and it was hard to say no, despite my warnings about her dog’s inability to understand as easily as our dogs did

that *Dark Star* should be of no concern to him and was off limits.

Retrievers are not as smart as shepherds, we all soon discovered. *Dark Star* flew down to the lawn one afternoon; the retriever bounded over and pounced on his chest, putting the bird into shock. He died cradled in my hands. I was stunned by the emotional impact of his sudden, pointless death. My premonition and earlier warning to Cheri and Leta led directly to a stark life lesson of the balancing act between love and loss. An unlikely relationship of mutual trust and wonder ended abruptly. I’d never grieved as much as with the death of this unique, gentle friend.

I brought *Dark Star* over to my folks’ yard for burial to avoid any additional grief if the dogs were to dig him up in our own yard. Soon, thereafter,

Leta and her retriever moved out—but *Dark Star* was no more. However, the profound privilege of his enlightening kinship has remained with and affects me to this day.

Not long after all that, our friend Jeffry called. Some kind of large, green parrot had flown into his mother’s yard, but she had too many cats around—could he bring the bird over to our place? But that’s a whole other story! ▲

Jim is 54 years old and has CF. He now resides on the edge of Joshua Tree National Park in California. A roadrunner, a dozen or so quail, a Le Conte’s thrasher, a variety of finches and sparrows, a couple of desert cottontails, two coyotes, a Cooper’s hawk and a pesky flock of mourning doves visit daily. He can be contacted at: james@back40publishing.com



Got Dog?

By Andrea Eisenman

My mom tells me that I came out of her womb saying, “I wanna doggie!” Obviously, I think she means as soon as I could talk, I said those very words. As a toddler, I had a stuffed dog that I slung over my shoulder saying, “Carry a doggie.” And every time I saw a dog on the street, I laughed and wanted to pet it. We had cats for most of my early years. I also had guinea pigs, hamsters, gerbils, rabbits and one snake.

It wasn't until I was 14 that we successfully got a dog. We named him Tony and got him from Bide-a-wee as an eight-week-old puppy. We had tried getting dogs before, but I was too young and it was too much responsibility for me and, of course, for my stressed-out, single mom.

Having never had a dog before, Tony was a lot of work, and training him to “go” outdoors was tough. We lived in Manhattan so it meant taking him out four times a day. My mom nearly lost her mind paper-training him. After about a year, we all adjusted and got used to what our responsibilities were. We loved him so much and received from him his love and his sense of humor. He always had us laughing from the way he greeted us when we walked through the door—stretched out like a Rubin nude on the loveseat—or walking on the table to get our attention. Since Tony, we have had quite a few more dogs and no more cats.

There was Max, a lab/greyhound mix from Bide-a-wee. He was very sweet and because he lived with my mom, who talked to him constantly, he understood a large vocabulary—uncannily. Then came Sadie, who was adopted by a boyfriend with whom I was living and me. It was a

couple of years prior to my transplant and it became clear I had to move home. Luckily when the boyfriend and I separated, he didn't fight me on custody. It was clear, she was my girl. The moment I set eyes on her through the chain link fence at, yes, Bide-a-wee, I knew we had made a connection. She gave me full-on eye contact.

She was a difficult dog the first year, while my boyfriend and I worked and she was home alone. Even with a daytime walker, she tore up the house. Garbage was strewn from one end of the apartment to the other. She dug a hole in the couch and one day helped

herself to some Frangelico liquor. She had extreme separation anxiety. I crated her but she hated it and escaped her captivity.

I ran her in the morning before work to tire her out, but it was taking a toll on my health to get up so early. When I moved home to my mom's and went on disability, problems were solved as I was home all the time and she had Max to play with. We had hours of fun and joy watching them play together, catch balls and tussle. For me, the best part of having a dog was having a cuddly sleeping partner. Max slept with my mom and Sadie slept with me. Sometimes I got both of them, one on each side. That was a bit too much dog in the bed. Max was 70 pounds while Sadie was 50. But I loved it as it kept me warm and I felt peaceful.

What I didn't know at the time and why I probably loved being around them and snuggling was that, that kind of intimacy with a person or pet releases a hormone called oxytocin. It is most common for mothers who have just given birth to help them bond with their newborn babies. I saw a NOVA special on PBS on dogs and they discussed this. In one study, they took blood from a person and her dog before and after they cuddled and for both, dog and person, their levels of oxytocin went up and stayed elevated for some time. The hormone helps people relax, evokes feelings of contentment and reductions in anxiety. No wonder I never wanted to be without a dog.

I always felt having a dog was healthy for me. It got me outdoors and got me to walk more. It got me to be social. You will not believe how many people will talk to you when you have



ANDREA EISENMAN
AND SADIE.

a dog. It is a great icebreaker. To this day, I have wonderful friends whom I had met in the dog run in my neighborhood. Being a dog-owner, I also laughed more. Sadie had a way of wooing strangers by shaking her booty at people and talking in a low howl. It sounded like, Wooh Wooh Whooh. This made me laugh so hard, as most people had no idea what to make of her.

She loved playing fetch and would drop a toy in my lap constantly. We played indoors with her favorite stuffed strawberry. She was a great catcher. She also liked to play goalie with her strawberry in a doorway; it was almost impossible to kick it by her. She then threw it back for another go. Very entertaining. Outside she ran and caught every ball, even when it was not hers.

Sadie also loved being around me

and my mom. She was always there for me while I did my hours of treatments or she joined me for a nap. And then, when it came time to do chest PT, she got in on the act. I would lie down on the bed and she crept in next to me, length-wise. As my mom pounded on my back or sides, I pounded on Sadie, who occasionally looked back at me as if to say, "This is necessary for me too."

Sadly, Sadie died a few years ago. I still miss her and her warmth and humor. I have since gotten a new dog. Ernie is a Boston terrier who has qualities similar to Sadie in that he loves chasing a ball and has some funny behaviors, like talking to people and shaking his lil' booty. We also have a ritual in the morning and that is to cuddle. I believe it is as much for me as for him. He just keeps me laughing and feeling happy. One thing

I debated before getting Ernie was – is it fair to get a puppy at this point in my life. I was six years post-transplant, how much longer could I expect to live?! What would happen to him if I died? I eventually overcame that guilt, especially after I met my husband and his new dog at the dog run. It would never have happened without Ernie.

I believe that my dogs helped me forget about my CF and my deteriorating condition. They gave me unconditional love and a better outlook on life. They can be a lot of work but, for me, it was worth it as the time and effort continue to pay off in my well-being. ▲

Andrea is 47 and has CF. She is a Director of USACFA and is the Executive Editor of CF Roundtable and Webmaster. Her contact information is on page 2.



In Memory

Anthony Panzara, 44
Chesapeake, VA
October 29, 2011

Bracha Witonsky, 35
Brooklyn, NY
December 12, 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

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





COUGHING WITH A SMILE...

My Special Dog

By Jennifer Hale

Well, hello again readers! I hope your holidays were full of blessings and good health! The topic at hand for this issue is: "Our Pets And How They Affect Our Lives". This is a topic that at one time I would not have been able to relate to, but I was blessed with experiencing what a pet can add to one's life - all the positives and all the negatives.

I grew up deathly afraid of dogs. It was so bad that when I went trick or treating with my cousin, he would have to get the candy for me if we heard a dog bark after we rang the doorbell. I would stand several feet away and wave as my cousin explained that I was scared of dogs, but I would like some candy. I think this fright came from the fact that when I was younger a dog chased me, climbed down my back and ran his paws with, what I thought were claws, down my hair. I ran to a tree and hugged it so hard, as this beast clawed down my back. I was scarred, and from that day forward I *never* got near dogs and was just so scared.

My mom and dad did not force me to get over this fear so my childhood was not filled with a Fido. I went as far as to have a fish and that did not last very long either.

Fast forward to an adult, married and living in the suburbs, and we get a call from my brother-in-law in Georgia asking if we would like a stray dog that he found. He said she was sweet, but he just could not keep her since he already had two dogs of his own. When my husband asked me if we could get this dog, the flashbacks of claws down my

back entered my mind. You would think I was attacked by Cujo (and I was not), but in my mind every dog was Cujo. So I said, "Why not? Let's do it! I need to get over this fear."

So we packed up the car and drove to Kentucky to meet my brother-in-law and to pick up our new dog. Let me tell you this was not a lap dog. It was a 75 pound, black and white, Australian shepherd mix. What had I gotten myself into!?

We decided to name the dog

Sophie. We started with Oreo 'cause she was black and white, but somehow in the little motel room the name Sophie emerged. For us, Sophie was born into our lives, in a small Louisville, Kentucky motel, during Derby days in April of 2000.

When we got home we were completely unprepared to have a dog. We had no toys, no cage and just a big pillow bed for our untrained dog. Every time we would open the door to go outside she would run past us and

down the street. She was gone before we could say sit. She *loved* people so she would stop along the way to visit with them. That gave us enough time to get in the car and down the street to pick up our runaway. She had some accidents in the house and for me, who is a neat

freak, I was not digging that! I was VERY upset and told my husband that I just can't live with this dog. It is too much for me to handle. We decided to give it two weeks, at least, and get her some training.

The trainer came to the house, which was nice, and in no time had her sitting, lying down, walking by our sides and recognizing her name. Slowly, Sophie came around, and so did I.

Sophie became my little baby. I can't tell you how many times my husband would hear me say, "Look at the little baby". I would even wrap scarves around her head and then laugh at her cause she looked like an old lady from a bad cartoon. She made me laugh, and laughing in turn made me cough, which was good therapy to get all my mucus out.

“Sophie made me laugh, and laughing in turn made me cough, which was good therapy to get all my mucus out.”



JENNIFER HALE

We came to realize, pretty soon after we had her, that she had a tremendously snotty nose. I mean snot would go flying all over the place from her nose. And it was yellowish/brown and I was thinking, "Does she have cystic fibrosis?" It was very appropriate for our dog to have a "snot" nose and lots of mucus production. I mean she really fit into the family! We were both now filled with mucus, only I had to wipe her nose and she could not do the same for me! LOL!

Sophie loved her walks. You could not say the word "walk" unless you were going to take her out for a walk. She knew the word and the tail started wagging and she was fired up to go for her walk. She would also run to the door and it was usually a chore to get the leash on her for her walks. We realized later in her life to not ask her if she wanted to go for a walk but to just put the leash on when she least expected it and then we would not have to deal with her convulsions of excitement. Sophie got me out-and-

about for a walk and that was great exercise for my lungs. I thank her for all the exercise she provided for me.

Our beloved dog developed what the doctor thought was cancer, only seven short years after we had her. She was so good about her medicine. This is ironic since I am, too, about mine. See, she fits in just perfect for us! We would call to her and say, "It's time for your medicine," and she would come running. She would take her eye drops like a trooper. I like to believe she knew the word medicine and knew she needed to get her drops, but she also got a treat after each session. So medicine to her could have meant, "Sophie, time for your treat." LOL. Whatever the reason, she came running and she was such a good and brave girl.

Towards the end of her short life with us, her health declined quickly. It was sad to see this food-motivated, walk-loving dog not want to budge from her pillow bed. Just to get her down the stairs to go to the doctor on the last day we had to tell her she was

going for walk in order to get her down the stairs. So sad! I tear up just thinking of it now.

Putting Sophie down was one of the hardest things I have had to do in my life. She went peacefully and with those around her who loved her most. It was funny when we were in the room, she went up to my husband and nuzzled him and then she came over to me for a nuzzle. It was like she knew what was happening and she was saying goodbye. I like to think she was saying thank you for picking me and loving me. So the dog who was never meant to be in my life enriched my life with a lot of love. She was the baby I would never have and taking care of her was a pleasure. May you rest in peace my special dog. Sophie came into our lives in April of 2000 and floated out of our lives on October 6, 2007. ▲

Jennifer is 39 and has CF. She and her husband, Mark, live in St. Petersburg, FL. You may contact her at: jhale@usacfa.org.

Information For People Who Travel On Airlines

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

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

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



WELLNESS

Motivation 101

By Julie Desch

How do you motivate yourself?

I get asked this quite often. I write a lot about exercise and how important it is in the quest to maintain lung function as we live and age with CF. I coach people and design great exercise programs that target every muscle group. I talk about and ferociously advocate the effectiveness of interval training as the best form of cardiovascular work. Lately, perhaps as a consequence of aging, I have become a big fan of mobility work, especially targeting the thoracic spine, apparently my Achilles Heel.

Yet this is all for naught unless the client or reader is able and willing to actually do the work. This, as you well know, requires the “M” word ... motivation.

Maybe I’m lucky. I never have had a significant problem finding motivation to move. I will have a lazy day, now or then, don’t get me wrong. But when it comes to exercise, my main problem has been staying focused on a single program long enough to complete it, as I am constantly searching for the “perfect” plan, and often get sidetracked with a “more promising” workout routine. Case in point: I am now on Week Five (out of eight) of a “Couch to 5K” program designed to take someone from the “couch” to running three miles (theoretically) without stopping. Alas, I just received my long-awaited P90X2 DVD set in the mail. What to do, what to do? A rather sick form of delayed gratification would be to allow myself to start P90X2 only after I can run that 5K. We’ll see how that works.

Here is what I do know about motivation to exercise. It changes as I do (and this likely will be the case for

you, too.) As a kid, I didn’t really need motivation. Kids just move. If you don’t believe me, have a toddler. Better yet, rent one for a day.

Adolescents often need a motivator, though. At sixteen, mine was to be the skinniest girl in my group of friends. Sick, I know, but this is how I discovered running. So, in retrospect, I’m glad I went through this phase.

My eldest son, who has not really been a fan of sports, has recently joined a crew team, and after a few months of hard training, has witnessed his testosterone-laden body undergo somewhat of a transformation. This is powerful stuff for a young ego.

Wanting to look better is a very powerful motivator. There is absolutely nothing wrong with this! Body image can be a significant issue for

those of us with CF, and getting on the *right* program can make a world of difference in how you feel about your body and even how it looks.

As I’ve gotten older, what motivates me is not so much how I look, but how I feel. This is a good thing, because aging is not a pretty process. At fifty-one, I go out for a 30 minute walk/jog because it feels so incredibly good when it is over. To me, this is worth the slight discomfort I experience during the jog phases of my outing. On really good days, it even feels good to be jogging. When I dig a little deeper in my brain and contemplate why this is a good feeling, I realize that when I am moving, I feel in control of my body. CF is not winning when I am jogging. I am winning.

So what motivates you? If you don’t currently exercise, but you know you “should,” here is an interesting experiment to try. I call it the “Why?” game. Think of a benefit of exercising regularly that compels you the most. If you are unsure of the benefits regular exercise offers to a person with CF, here are a few to consider:

- Decreased rate of loss of pulmonary function (I know that is an awkward double negative, but I am trying to be accurate, according to the studies out there)
- Diminished loss of bone density
- Improved quality of life
- Improved functional capacity (this means ability to “do stuff” with less effort)
- Increase in appetite
- Decrease in depression and anxiety
- Increase in weight (if needed, and body is supplied with enough nutrients)
- Improved body image



JULIE DESCH, MD

- And here's the grand finale: Fit people with CF tend to live longer!

I probably forgot a few, but that should do for now. Pick the one that matters the most to you, and ask, "Why do I care about that?"

Write down your answer and next ask, "Why do I care about *that*?" Then, look at that answer, and ask ... well, you get the point. Let me suggest at this point that you do this exercise with paper and pen – remember those? This way, as your motivation wanes, you can go back and remember your thought process to get psyched all over again.

When I play this game with coaching clients, we will often go several rounds into it when there will be an "ah ha" moment. Sometimes, there are tears. Mostly though, there is a very strong clarity of purpose, and *this* is his or her motivator of the moment. This will get the client out the door, or on the mat, or to the gym.

Finding the strong motivator is not enough, though. What also needs to happen during that moment of

clarity is to identify an achievable goal, and then come up with a plan to get there. A gale force tailwind is not enough. You need a specific destination, and you need a map! And don't forget the lesson of the movie, 127 Hours ... tell someone else where you are going! They can help you keep on track.

To recap: Make an exercise related goal in line with your deepest purpose uncovered in the "Why" game. Design your roadmap ... a daily plan that is appropriate for you at this stage of your life. Commit to it. Then go do it. It really is not complicated. When you have a day where you feel lazy (not sick ... that is something entirely different), reread your reasons for your commitment to your program and *just go do it*.

If you are breathing, you can exercise. If you want to continue to breathe, you *need* to exercise. ▲

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



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.

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IN THE SPOTLIGHT

With Andrew Golubic

By Jeanie Hanley and Andrea Eisenman

Andrew Golubic: 26-year-old with CF

Occupation: actor and restaurant server

Andrew has been physically active all of his life. During his sophomore year in college, he started lifting weights on a regular basis and felt that major benefits in his health followed. “CFvoice.com” interviewed him because of his desire to motivate others to exercise. After interviewing this exercise buff, I was inspired to use the weights lying around in my garage. I hope you are too! Heeeeeere’s Andrew!

When were you diagnosed?

I was diagnosed at eight years of age. Although CF was suspected when I was a baby, the hospital said the tests were fine. Repeat testing was done, but none of the tests was positive. Finally, my mother, who knew something was wrong, took me to another hospital where the sweat chloride test was found to be positive.

What are your symptoms of CF?

Only my lungs are affected. When I was younger, I had been taking enzymes, but during college, new tests showed that my pancreas was working well, so I stopped and haven’t needed enzymes for about five years. Up to my college years I had been very skinny (6’2” and 165 pounds). Once I started weight training, my metabolism increased, I gained weight and somewhere along the line, my pancreas kicked in. I now maintain my weight at 195 pounds.

I also feel lucky, now, that I need to use only Pulmozyme, hypertonic saline and Advair. I have albuterol but haven’t needed it for many years now.

Where did you receive your care before coming to USC and how was the transition to a new area and CF Center?

I grew up in Ohio and received care there. Moving to Los Angeles by myself was a smooth transition. I had friends out here who let me stay with them until I found my own place. As for the CF care, one of the nurses at Akron CCF was a good friend of the nurse at USC CCF. So the Ohio CCF was in contact with USC and by the time I came out here I felt familiar enough with USC and they knew about my CF history too.

Were there any insurance issues with the transition?

The major issue was the transition to GHPP from my dad’s private insurance. There were six months that I had no insurance while waiting for the GHPP to kick in. Luckily I had amassed enough medications to carry me through, but it was nerve wracking not knowing if the meds would last, and whether I might not be able to receive care. Even though I felt fine, missing a CF visit meant not receiving the reassurance that I was truly doing fine.

How did you become interested in weight training? Was it always a way of life?

I’ve always been physically active – playing baseball, football and basketball in high school, and considered myself to be in shape. After a year in college, I moved in with my brother, Dennis, who has always been big on fitness and an avid bodybuilder a la Arnold Schwarzenegger (referring to the weight training aspect of Arnold’s life only, we hope!). He pushed me to work out with him (not with Arnold,

of course.) Dennis felt I’d be healthier all around with bodybuilding. He told me about Franco Columbo, another famous bodybuilding guru and actor, who could blow up a hot water bottle until it popped. My brother felt that exercise would help increase my lung capacity. He pushed me to excel.

Now it’s become a healthy addiction where I want to go to the gym every day. If I miss a day, then I often feel sluggish and tired that day. On those rare days it also affects my ability to effectively interact with restaurant customers.

What was your most memorable exercise moment?

The first time I lifted 300 pounds. It felt awesome, similar to the first time you hit a homerun. I was speechless and felt tingly, ecstatic. I told myself, “I did it!”

Are there other exercises you enjoy?

The cardio [aerobic exercise] I like most is riding my bicycle. I hate running. Maybe sprinting is okay. I still play basketball and softball. And right now I’m trying to join a baseball league. I’ve always been very competitive. People always tell me to slow down, but my feeling is that if you play, you should give 100%. Go full speed around the bases.

I enjoy lifting weights the most because I love the way it makes you feel and the way it affects you mentally. Growing up with CF, I was given predictions that I’d always have a small build and difficulty increasing my weight. Sometimes it’s those comments that motivate me to maintain my workout routine. I’ve noticed that my lung capacity has increased since

lifting weights, so much more than cardio alone.

Please give us an idea of what your daily routine is like.

Soon after waking, I inhale meds while wearing The Vest® and playing video games. After running errands for a few hours, including auditions, I head for the gym about 3:00 p.m. for a 1 - 1 ½ hour workout. Then off to work around 5. I'm eating constantly throughout the day; to get to 210 lbs I would consume around 5000 calories daily, now it's more like 3000-3500.

How did you choose an acting career?

I've always enjoyed entertaining people. In school, I was the class clown. Having said that, I had originally planned to be a premed student and become a doctor. In my junior year of high school this changed when, through the Make-A-Wish Foundation, I was able to watch the filming of "Men In Black II" and met the director and cast members such as Will Smith and Tommy Lee Jones. Watching and meeting them was amazing and inspired me to pursue acting.

How do you stay motivated to work out regularly and to continue to pursue what most believe is a difficult career?

My parents always encouraged me to go for it in whatever I did. They wouldn't let me retreat and were adamant about not letting CF or any other obstacle hold me back. I believe that it helped that I was diagnosed relatively late, at eight years of age, because my mindset already was to push myself as much as possible, not just in sports, but in all aspects of life.

My parents also raised me to not be embarrassed by CF. All my friends in high school, and today, have seen



ANDREW GOLUBIC

me doing treatments. In high school, friends asked me to smoke and I would flat out tell them that I had lung disease and it wasn't good for me. As a consequence I've been very open about most areas of my life. Because of that openness, I was asked to interview for "CFvoice.com". In a way, having CF has been a blessing in disguise because it's made me who I am and given me opportunities I may not have had otherwise. I feel I've become stronger not just physically, but mentally too; more than if I didn't have CF.

I also have to give so much credit to my brother, Dennis, other family and my friends for being very supportive and pushing me to better myself. I'm still very close to my family and talk to my parents and brother several times per week.

How does CF affect your getting roles?

So far it hasn't made any difference and I don't see it being a problem in the future. Both physically and mentally, my health is a major part of

my life and I plan on staying healthy so I can handle anything thrown my way. When people look at me they don't see a "sick kid"; they see me. Hopefully, they like what they see.

On the set, how do you find time to maintain your CF routines and deal with obstacles such as smoking?

As far as smoking goes, I would let the director/producer know that I would prefer not to and explain my reason. If they really want the character to smoke, I would have to find an alternative. There are herbal replacements, which I wouldn't say are good for someone with CF to smoke, but it is an alternative to cigarettes. As for medicine, exercise etcetera, there is enough down time on set to get things done; and, if not, I would just have to get up early and take care of what I need to.

What kind of work as an actor do you prefer and what is your dream role?

At first I wanted to get into comedy, but then I started to realize that I would rather be an all around actor. There is a different feeling of satisfaction for every type of role. I love making people laugh, but the feeling you get when you make someone cry is amazing. To know that you have the ability to move a person that much is great, and then there is yet another feeling when you pull off something that makes the viewer go, "Whoa!". Best case scenario would be to mash them all up and take the world by storm.

My dream role has recently been filled. I would have loved to have the chance to play Jon Snow on the show "Game of Thrones", which is based on a series of books that I am very fond of. I still think it would be amazing to

Continued on page 30

Calling All Writers

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

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

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

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

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GOLUBIC *continued from page 29*

be a part of that show. Another dream role would be to play the comic book character Deadpool. I also want to be in a western and I like fantasy. So I guess I have many dream roles, but at this point in my career every role is a dream role.

Anything else we should know to get a sense of what being an actor is like for someone with CF?

I don't think it is any different from being an actor without CF. We all struggle, we pay our dues, and we work hard trying to make our dreams reality. It's not an easy road and if you think it is, you are mistaken. Some people get lucky, most don't. What CF has taught me, I guess, is to my advantage – and that is to appreciate life. We have to live while we're alive, plain and simple.

What do you see yourself doing in five years?

In five years I plan on being successful as an actor. I may not be a superstar but, who knows, maybe I will. The goal is to make a living doing what I love to do. I also want to travel the world. I have never been out of the

United States. Mostly I want to inspire people ... and also take up sword fighting classes.

Any last words of encouragement to those of us who need it?

My main thing is don't let CF keep you from doing something. If it doesn't harm you, then go for it. Don't do it just because you have CF, but because you want to be stronger mentally and more physically fit.

Many thanks to Andrew for agreeing to be interviewed, his insights into the world of exercise, his honesty about his life, and overall candor. ▲

Jeanie Hanley is 49 and is a physician who has CF. She is a Director of USACFA. Her contact information is on page 2. Andrea Eisenman is 47 and has CF. She is a Director of USACFA and is the Executive Editor of CF Roundtable and Webmaster. Her contact information is on page 2.

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



Mailbox

Great publication! Thank you!

*Donna Mueller, PhD, RD
Philadelphia, PA*

CF Roundtable is always an inspiring and enjoyable read. Thank you to each contributor.

*Jeanette Trecek
Charlotte, NC*

I am married to Kevin, who is 42 and has CF. He was diagnosed at age 2½. His sister, Karen, died in September 2008, at age 41, from complications of CF. Kevin and I have been married for 15 years and have 11-year-old Ellie and 9-year-old Matt.

*Patti McDonnell
Bolingbrook, IL*

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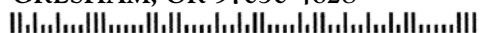
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features on the site that are now available. The new *CF Living* is designed to help you work more closely with your Care Team, learn about treatment options, and provide interactive educational resources so you stay informed. Enroll today at: <https://www.cfliving.com/> to begin taking part in this informative program!

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