



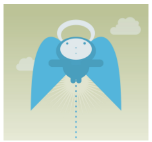

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ECD GLOBAL ALLIANCE NEWS
ECD Global Alliance News

Kit's Angels

by Mark McElwee

In the fall of '05, Kit, who was 25 then, and the rest of the family booked a trip on the ECD cruise. What fun it's been. Exotic destinations. Interesting people. Everyone should have a chance to experience the adventure! Ha! Meeting others who struggle daily with ECD has been an eye-opening event for us. Irony intended. ECD has blinded our daughter, and we've found that to be a rare situation.

But as we have shuffled from hospital to hospital and doctor to doctor, we have run into some angels along the way. The angel stories will make you smile. We cried a lot and got angry and prayed and cursed some. All that. As time passed, though, two truths became clear to me. The first truth is that even strangers can be incredibly kind. I'll cover the other truth later.

I expect my friends to help out in some way, and some have been extraordinary like Jeff who I coached thirty years ago in age group swimming. He handed me a check for $500 and told me not to dare give it a thought. Kit's psychologist, Tony, sees her every week and all he'll let us do is treat him and his wife to dinner. I coached his Michael over twenty years ago. Fellow coaches and associates from the Suburban Aquatic League raised A LOT of money for Kit's expenses and we've been fortunate to be able to put that aside for a rainy day.

But the strangers … Wow! Have tissues ready. In the very beginning, we spent a nerve wracking morning in neurosurgeon Peter LeRoux's office and it was decided that there would be cranial surgery to remove the tumor that started it all. We were scared and beaten up, but parking in Philadelphia is a fortune so I asked the receptionist if they validated parking. "No. I'm sorry." I had my hand on the door when she suddenly got up and firmly told us to wait. She came back from another office and handed us a pass. "This will cover the parking. And here … These are vouchers for the cafeteria in the hospital. You've had a terrible morning. You should eat." Kit and boyfriend Drew and mom Christine and I left and followed her orders. She was right. Her name is Grace. Amazing Grace. She gets that all the time, but that's not what motivates her. She just cares. Kit's tumor was removed and diagnosed as LCH but the tumors behind her eyes got worse and the doctors have concluded that Kit might actually have ECD and LCH and even a course of radiation didn't touch them. The doctors were and continue to be terrific, but we were due to run into more people like Grace, little people, who don't hit home runs but keep the game going with bunt singles that become RBI's.

In another installment, you can find out the details of ECD in our case, but for now it's enough to know that Kit got very sick. She lost her sight when a tumor on her heart caused a collapse during which her blood pressure dropped and the tumors on the optic nerves were able to tighten up and crush them. But that collapse put her in the Hospital of the University of Pennsylvania for the month of August in '07 and nearly killed her twice.

We met Holland there. Holland, a certified nursing assistant, was assigned to Kit's area during that month and she adopted him as another big brother. Holland just did his job, but there was always a gentle voice and a gentle way about him. Holland always found time during his shift to spend some time with Kit. When we visit Rhodes 7, one of the cancer floors, Kit and Holland share a hug. We don't bother them until they are ready to break on their own. Kit holds him tightly and he does the same. Holland doesn't always tear up, but Kit does. And we do. And sometimes Holland's co-workers do, too. We have a drawing of Kit that Holland did for us. Bittersweet because Kit cannot see it. It's even more bittersweet that Kit has never seen the man she loves so much that she isn't kidding when she refers to him as her brother. Holland's contribution to Kit's recovery is all about her emotional state.

One night during that lousy August, I was waiting for the elevator and I was aware that someone was behind me. I turned and saw a cleaning lady with her cart and broom. Eye contact. My chin was somewhere around my ankles. "Don't worry, Honey. We pray for all of 'em all the time." I did thank her, but I was three floors down when the kindness of those words really hit me. Tears. Why should she have cared? But she did. I was relating the story to a couple of cleaning staff months later. The crisis had passed, but I wanted them to know that they were important. One lady smiled. "That was me." Her name is Mabel. And she was perfectly okay when I hugged her and thanked her and then she told me, "I know who your girl is. She don't know it, but I prayed with her last night. She was sleepin', but I took her hand and said a prayer." Mabel prays for everyone on that floor while she sweeps the dust from under their beds.

Kit is a certified open water

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"Simple Simon Says…"

Fatigue

Many ECD patients find that fatigue is a significant problem that they have to learn to deal with. I presume that they mean that they feel too tired to undertake any activity, or that they feel excessively tired due to the work that they have done. I count myself fortunate that this is not a problem that I have had myself, particularly. But that may have something to do with "goal-setting and expectations" (scary, trendy words; ooh err, do I dare use them?). Perhaps the reason that I don't have so much trouble with fatigue is merely that I don't set very challenging goals, and I have low expectations, which are nearly always met! This IS one way of meeting the challenge!

On an ECD chat this past winter, the wife of one of the ECD patients had been shoveling snow outside, and she was tired out, hot, and sweaty! When Kathy sent out the Draft Summary of the Chat I let Kathy in on one of my fatigue relievers.

"If there is to be ANY EFFORT involved, let SOMEONE ELSE do it,

then YOU won't get so tired."

There are some more sensible possibilities for controlling the amount of effort required for everyday activities:

Internet shopping
Postal services
Vegetable box deliveries
Dishwasher
Domestic and gardening help

In olden days my mother could telephone an order for some groceries to the store. They would then deliver. There were also a couple of guys who drove around in pick-ups to people's houses, and you could buy stuff from them directly. A mobile store! Over recent years quite a few stores have started to let customers place orders for goods using the internet. The goods are then delivered to your house at a time that you have arranged. This service is brilliant for people who do not have enough energy or are unable to go to the store themselves. These services are particularly good for delivering the really heavy necessities of daily life. Dog food, bags of flour, washing powders and liquids, and, of course, cans of beer and bottles of wine!

It is pleasantly surprising to find out how much can be delivered by the postal service. My biggest problem is that you cannot predict when something will arrive. The postal services usually like to have an alternative delivery place (like the back garden (yard in the US) or at the house of a neighbour).

Some vegetable suppliers will let you make a "regular" order and deliver direct to your home. We have had such an arrangement for a few years, and it means that "something" fresh arrives every week.

A dishwasher is a most wonderful machine. If you have always had one, then you will realize how great they are. If not, I thoroughly recommend that you go and buy one straight away!

Help around the home is great to have, but, it depends a lot upon the people who are prepared to provide it. There are many jobs around the home that we aren't able to do now, and, if we can get help, that is very useful. It doesn't have to be help inside the home. Help with the garden/yard work is also very handy.

I think that we need to use these methods when we can, to try to reduce the overall amount of work and effort that we need to put in; and to make us feel better about doing what we can, and not doing what we can't!

Yours,
Simple Simon

~You gotta love living, kid,
cos dying's a pain in the ass.

About the ECD Global Alliance

www.erdheim-chester.org
support@erdheim-chester.org

For those of you living with or caring for someone with Erdheim Chester Disease (ECD), you know how frustrating it can be to find answers and support for the daily struggles faced with such a rare disease.

In Spring 2008, a small number of ECD patients and their loved ones decided to form an unofficial group with the intention of providing support, raising awareness, and promoting education of ECD.

Thanks to our 100% volunteer effort we have accomplished many things in just a few short months: created a website devoted to ECD; established online chat room and continue to hold weekly chat sessions; facilitated a teleconference between Dr. Kurzrock, an ECD knowledgeable doctor, and patients; found doctors (Dr. Haroche and Dr. Vaglio) doing research in ECD and made that information available to patients; published a patient log that summarizes numerous ECD cases; published a brochure on ECD; provided the first personal and patient-to-patient support structure known for ECD patients; and we continue to do more!

History of My Signs and Symptoms of ECD

By Dale McAllister

My earliest indication of something wrong was when I was diagnosed with Prostate cancer in June 1990 and in November 1990 I underwent prostate surgery. Prior to the surgery a bone scan showed hot spots on my right hip and the technician doing the test remarked on this. However, nothing was ever mentioned about the "hot spots".

In 1997 I had developed borderline diabetes, which was controlled with exercise and diet. I say this because when I started my treatments they started me on prednisone and that shot my blood sugars out of site so they put me on Insulin. I am getting ahead of myself. I remained cancer free from October 1990 until March 1999 when a biopsy indicated I had a recurrence of Prostate Cancer and I underwent 38 radiation treatments at a local radiation doctor's office.

Sometime in 2001 I was complaining of leg pain and so an x-ray revealed a torn Meniscus. The x-ray was followed in December 2001 with an MRI just prior to knee surgery. The doctor expressed concern when he said, "Whose x-ray is this? He has prostate cancer of the bone". I explained that I couldn't have it. The most recent PSA was -0.1 last month. I proceeded with an Arthroscopic repair of a torn meniscus.

On January 16, 2002 a CT guided needle biopsy of my right femur was attempted without success. The doctor was unable to get needle into bone and was therefore unable to obtain material for biopsy. I tried to make light of the situation by suggesting to the Doctor that I had a hammer in the car that might work.

The leg pain continued along with fever and chills which seemed to come on every evening between 7:00 and 7:30PM. This went on for quite some time and finally in August 2003, one doctor sent me to another doctor who sent me for blood tests and bone marrow imaging. A test to rule out osteomyelitis was done in September 2003. The final diagnosis at that time was "probably Paget's disease of the bone".

In spring 2004, while on vacation in Florida, I saw a doctor who recommended a CT scan of the abdomen and pelvis. During the scan, I told the technician I didn't know why they were doing that as I could hardly breath so she then took CT further up toward my neck, where it was discovered I had a pericardial effusion. I think this saved my life because in about three minutes they took me into the ER where a CT guided needle drew out 1000 CC worth of fluid from around my heart. The following day in mid-April, 2004 they decided to do an exploratory Laperoutomy and they took 8 biopsies of a mass they found in my stomach and then two days later they operated again on my heart sack because it had once again filled up with fluid. This time they withdrew 1200 CC's of fluid so they put windows on 3 sides to keep the sack draining.

A week or so after being in the hospital I went to my doctor and he suggested I go to Mayo Clinic in Jacksonville, Florida for further diagnostic tests as he did not know what the masses were. During the following 5 days I had every kind of test known to man or beast, and on the fourth day of testing they did a PET scan and the doctor said he needed to send me to the hospital because there was a mass around my aorta and airway. So off I went to St. Luke's Hospital on Thursday, and on the following Monday they did surgery to get a biopsy of the mass that was right above my heart. Following this surgery I went back to Sarasota, FL where my doctor said I needed to go back into the hospital for 24/7 days of Chemo treatment as it was at this time on June 17, 2004 that I was diagnosed with ECD. The treatment made me very ill as they were giving me 2-CDA. On July 1st they gave me 2-CDA for 4 days in a row. Well I was a bad boy and said no more it made me too sick. My doctor suggested we return to Georgia for a month or two which we did and it worked.

When we returned to Florida my doctor said lets try one more thing. I said I would as long as it didn't make me sick. The doctor said she had cured a man with leukemia with this treatment and I said okay and off we went for 1 treatment a week for 6 weeks. The treatments made me tired, but not sick. All the while during these treatments I continued to have my blood tested to monitor my red and white blood cells which, if they were too low, I would receive booster shots as this was very important for the immune system. I also had been having CT Scans every three months during this period, so we knew what the treatments were doing and well after the 6 weeks there were no new masses. And to this date 4/5/09 there are no new masses and I am not on any treatment plan at this time. Yes, I still have leg pains and thanks to our good Lord I am still alive. I feel very luck that I am still able to walk with a cane. I sit a lot as I like to work in my shop building things.

I want to say that throughout this entire ordeal, my wife Barbara has been at my side giving me the necessary strength to go on and fight this disease. I talked to her this morning and I would like to donate my body to the Medical College of Georgia so they can study the effects of this disease on the body, the bones and the masses, and whatever else they find so hopefully they are able to help anyone in the future that has this disease. Then when they are finished they can return me to Barbara in a jar and let her throw me away. I am going to be in heaven with our Lord and Savior.

Online Chat Information http://www.chatzy.com/427437211406

The ECD Global Alliance hosts scheduled online chats each week. Anyone affected by ECD is welcome to attend. This includes patients, caregivers/carers, family members, medical personnel, etc.

For those who register with the ECD Global Alliance, emails are sent out announcing each chat session and a summary email is sent following each chat session. The time for the next chat session is also always posted in the chat room. If you have not yet registered with the group, you can always enter the chat room to find the time of the next scheduled chat session.

The chats are open for any discussion topic within reason. Often discussed topics include: ECD diagnosis issues, treatments, tests, knowledgeable doctors, symptoms, treatment side effects and sometimes just friendly discussion about other pleasant things happening in participants' lives. Most who attend the sessions have found it a good way to meet others whom they can correspond with outside of the chat sessions. For some this has proven to be a good way to build a support structure of others who are interested in learning as much as they can about ECD and providing mutual support to each other.

We invite anyone affected by ECD to attend and participate in the chat sessions.

(Continued from page 1) Kit's Angels

SCUBA diver. She has also adopted her instructor, Butch. Her diving experience is another installment, but Butch is a lot like Holland. Absolutely kind. Patient. Patient. Patient. Kit was his first handicapped student and blind. But he treated her like his own and was so happy with her that her first dive was close to twice the depth of the other beginners. She's that good. Butch was that good. The local NBC affiliate did a story about Kit's accomplishment and when Kit was interviewed, Butch, the master diver, was wiping away tears. Angels cry sometimes.

Christine is THE mom. Does more for Kit than she should. But when we talk of angels we have to include 39-year-old Mark – K-9 officer, former Army sergeant, professional lifeguard and the driving force behind Kit's diving adventures and 22-year-old Cassie – art student, lifeguard, photographer -- the little sister who, when the "kids" were SCUBA-diving in the Living Seas at Disneyworld, was the other certified support diver on Kit's left hand. Christine and I had one of our proudest parent moments as we watched other spectators marvel at the ease with which the young blind woman navigated the reefs and, guided by her siblings, touched rocks and waved at us through the glass. Some lady at Disney walked past and saw us trying to keep dry with trash-bag ponchos and she handed my wife a brand new poncho in its package. "Let her use this." She just kept on walking. She might have had wings under the poncho she wore. Hard to tell.

Here is a second part of this piece. As hard as it is to watch our Kit struggle with the losses and the threats from ECD, when we look around, we see people who have it worse.

Rhodes 7 is a cancer floor and we could tell that there were people who would not be in this world much longer. How does that staff work there every day and stay sane? We were there for a lot of chemo and we saw the families gathered around loved ones helping them one last time.

One of Kit's high school classmates has been in a wheelchair and non-communicative since an auto accident back in '99. His mom saw me at church and offered to help with Kit, because she and her husband had a routine for Ed and could squeeze us into their schedule.

Another classmate of Kit's will get his PhD in bio-engineering soon. Kevin is a millionaire at 29. Part of his work toward the PhD involved a very lucrative invention. But Kevin has a sister who has been through a couple of liver transplants and the family sweats the organ rejection difficulties every day. All of Kevin's money and accomplishment can't fix Jen's liver.

We were waiting for a coaster ride at Disneyworld and in another wheelchair a dozen places behind us was a family whose son, about 10, was all contorted at bizarre angles. Kit could manage to walk when it was time to climb into the ride. That boy's parents had to lift him to do anything. He could see, but he couldn't do much else.

We are new at this ECD experience, but Kit's doing pretty well from what we see out there. No pain. No organ involvement. Lesions on the bones are gone. Tumor on the heart is gone. Tumors behind the eyes are reduced to the point that they don't press on the nerves anymore. Did their damage, though! Pituitary involvement is less. Kit's a little shaky on her feet, but at the end of '07, she could hardly get her head off the pillow. Interferon and 2cda. And too much prednisone. If something happens to get her vision back, she really won't be in such bad shape.

ECD – I even consider not capitalizing the initials. I hate it that much. It's stolen so much from a lot of people. Mark worries a lot about his "little" sister. I found that out when his friends told me that he talks about it all the time. Cassie does pretty well when she's at college and not here. In her case, she gets frustrated sometimes because EVERYTHING is about Kit now. Drew is no longer in Kit's life. Can't blame him, but we all miss him. Good guy. Christine is tired all the time, and since she doesn't talk about ECD, she fusses about stupid little stuff. She actually can cry over spilled milk. But Kit (Christiana) is alive after close to four years and she's getting better for the most part.

Several times a week, someone asks about Kit, reminds us that there are prayers being said, asks if there's any help we need, or reminds us that we should take care of ourselves. And, sad to say, we continue to bump into folks who are going through worse traumas that are just as unfair and cruel. When we are down, we can think about Ed and Jen and kids like that boy in the line and we can recite the litany of the angels we know – Butch, Mabel, Holland, Grace, a host of friends and acquaintances, and that lady in Disneyworld – whoever she is - with wings under her poncho.

If you have any comments or would like to submit an article for a future newsletter please email the editor at stanceforlance@hotmail.com. Feedback and input is always welcome. Together we can make a difference!