

A MAN BLESSED

By
Walter W.
Comer



DEDICATIONS

I owe my survival and this tale to my God, my rock of a wife, “Kristine” (I love you), our Yorkie, “Curry” (Thanks for the smiles, the laughter and the love li’l buddy), our loving family, our wonderful church kin and, of course, my ever patient doctors.

Mom, thanks for the ear to bend, the familiar vacation spot where I always feel welcomed, the home cookin’, the laughs, the extra thick skull (Especially with Pop’s genes thrown in), for my little sister and brother and for all the love and patience when you and Pop realized I was never going to grow up. I love you both.

Kathy Brewer, the Erdheim-Chester Global Alliances fearless leader, thank you so very much for sacrificing so much time to get fellow ECD sufferers in touch with each other and for helping get us “on the map”, so to speak.

As far as our chat group and all other supporters, “Thank You”. God heard and answered your prayers, and we have felt and appreciated your support in all its forms.

God bless all of you,
Walt

RELIEF?

A Xanthogranuloma. After six years of unquenchable thirst, drastic fatigue and a depression that shook our marriage, we finally had a name for the stranger in my head. I felt so relieved. My naïve thought was that, once we knew what the problem was, I'd get a shot or some medication, and I'd be cured. How often is life that simple, though? Turned out I'd just become a member of a very elite group. An MRI and a follow up appointment with my oncologist revealed that Xanthums rarely grow in only one area. So, next on the calendar was a full-body bone scan.

The images from those scans made it appear as if I were filled with an odd arrangement of neon bulbs. They showed growth from my pituitary gland down surrounding my carotid arteries and then reaching back up very near my optic nerves. Also, one kidney, the aorta in my intestinal cavity and both legs from the knees down were shown to be involved. The growth around my pituitary gland was found to be interfering with my Testosterone levels, pointing out the likely cause of my fatigue and depression. I had become one of 178 people in the last 77 years to be diagnosed with Erdheim-Chester Disease. That number has risen to between 300 and 350 known cases, and it is thought that this illness is still under-diagnosed. It will probably remain so until the medical profession understands more about ECD, its symptoms and treatments.

AMBUSHED

Well, next the words spoken shook this wedded couple to its very core. The oncologist told us, with the way the images looked, he had no idea what my life expectancy may be. *LIFE EXPECTANCY?!!* I knew I was sick. But, it had never crossed my mind that this disease could end my life. My wife and I were obviously caught off guard and in shock. Seeing how shaken we were, the doctor gave us some privacy in the exam room, where we held each other, frightened, in tears and feeling very alone.

In July of 2007 I began Interferon injections, which really took the wind out of my sails. Shortness of breath, flu-like symptoms and heart palpitations literally took me to my knees more than once at work. I tried to "Man-up" and continue my duties. But, the night I went to the floor with a palpitation that completely disoriented me and left me hardly able to breathe, I got the message that the job was over.

I was admitted to the Cardiac Ward that night, as the symptoms sounded like a heart abnormality. One of the nurses and none of the doctors had heard of Erdheim-Chester. So, they insisted that I be kept on that floor with that tasteless diet. Yuck! But, it was only for one night, and I survived with the help of my wonderful wife. She sneaked a sub sandwich up to my room in her purse, *my Hero* (pun intended), and I was quite a happy man.

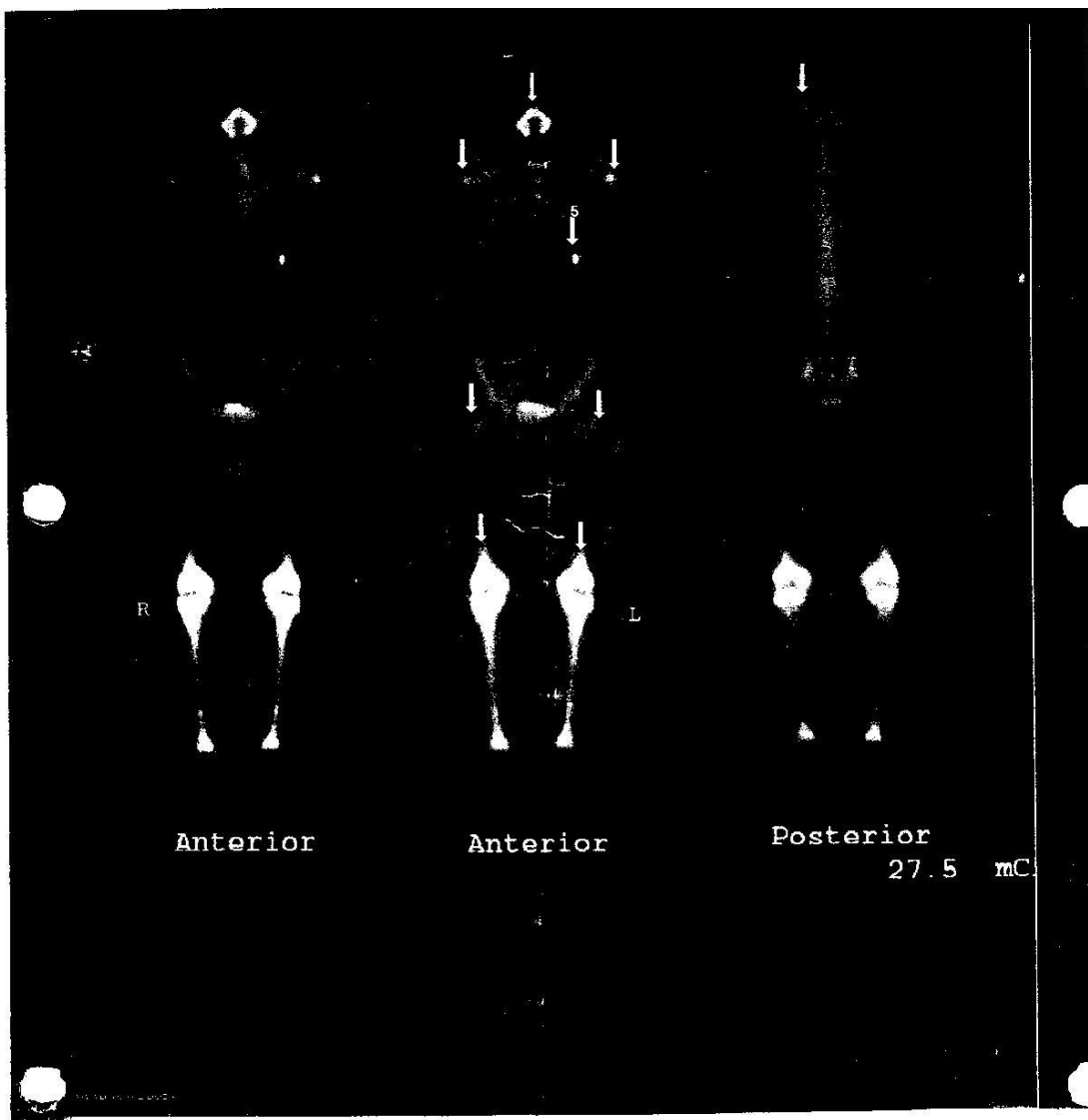
Erdheim-Chester Disease

Erdheim-Chester Disease was first described in literature in 1930 by pathologists Jakob Erdheim and William Chester.

Basically, ECD is when the body produces too many infection fighting cells, or Histiocytes. These cells gather in the loose connective tissues of the body, causing the tissue to thicken. Organ failure can result.

Areas of the body affected include long bones of the legs and arms, skin, tissues behind the eyeballs, lungs, brain, pituitary gland, kidneys, abdominal cavity, the membrane surrounding the heart and adrenal glands. Other organs can be affected, but this is more rare. Different combinations of organs can be attacked.

There is no known cause and, thus far, no cure. Some drugs, such as Interferon, have been shown to slow the growths, if not shrink them somewhat. Methotrexate and Cladribine, or 2cda, also show promise, but fall short of being considered typical treatment.



Bone Scans, 6/2007

GETTING MY ATTENTION

Still reeling from all that had recently been discovered, it never occurred to me that I was feeling sorry for myself and that this was giving ground to the disease. It had also slipped my mind that my God has more than enough strength and love to carry us through frightening times. I had already given in, was using a cane to keep my balance and, except for going to the mailbox, sat on the sofa all day just waiting for the inevitable. One morning as I maneuvered slowly back up the hill to our house after getting the newspaper, I was stopped in my tracks by a voice in my head.

“STOP IT!” I was stunned. I’ve talked and listened to God for many years. But, I can’t remember His ever yelling at me.

“You’re letting this disease win, and you’re not trusting Me with it”. After receiving a frightening diagnosis, experiencing extreme pain below the knees, having poor balance due to the pain and dealing with the side effects of Interferon, I had settled into acting sick. I used a walking cane, moved very slowly and a blanket covered me all day and into the night. I allowed one of our church congregation to mow our yard. Without even thinking about it, I was letting the enemy win. I simply caved in.

After being rightfully scolded and spending time in prayer, I returned to the house, talked with my wife about what had happened and I tossed the cane aside. I’ve refused its assistance since that day. I have also re-taken mowing my own yard, though it takes two or three days, and have plans for horticultural improvements.

Another thing I’ve learned through prayer and experience is that defiance, fight and attitude are not options when one’s life is threatened. We each have loved ones that are fighting the battle with us, are concerned about us and are our support system. Giving in and letting sickness win would leave a hole in their hearts that can’t be filled. Sure, I’d love to go to sleep and wake up to a new world, a world with all my tears wiped away and “no more sorrow, pain or death” (Rev. 21: 4). But, what about the folks I’d leave behind until that time arrives? I owe it to God and all who love and care for me to defy this illness and live my life to the fullest. If or when the time comes and this illness finally finds a way to beat me, I want to leave those I love with wonderful memories. I don’t want their thoughts to be of a sad and beaten man. I do defy this disease and refuse to let it take me without one heck of a fight. I will leave it bruised and battered!

CURRY

Due to my medications, leg pain and lack of balance, I was placed on disability and was unable to drive more than five or ten miles. So, I was often trapped at home, learning how to fight this battle and waiting for my wife’s shift to end. I soon became very lonely and was slipping back into a depression that medicine couldn’t help.

I spoke with my wife about this and, **“Godndog”** has to have something to do with what came next (Just search **godndog** on a computer). She asked me if I wanted to get a dog. I

cleared that suggestion with our landlord and soon after, one of her co-workers asked if anyone wanted to adopt a little Yorkshire Terrier. After prayer and some discussion, she gave the person our contact information.

Learning about our situation and that we had prayed about having a dog seemed to seal the deal. It didn't hurt that we attended the same church. It wasn't long before the little guy's owners called my wife and set up a time and date to see if we fit. "Curry" took to us both immediately, and we became a family that day.

He certainly proved to be one of God's many tools that quite literally saved my life. He needs to be taken out for 30-45 minute walks as close to every day as we can manage. So, I get regular, vigorous exercise. Plus, I've been throwing in some push-ups, weight work and abdominal work to balance this activity out. He needs to have play time and mental stimulation, which keeps me mentally stimulated finding new places for me to hide or to hide his toys so he can hunt them down. His smile and personality are so adorable that they bring laughter and smiles several times a day, and laughter is truly good medicine. My favorite bonding moment, though, came one gray, February afternoon while I was still adjusting to the Fentanyl patch and Interferon's flu-like side effects. Curry had been with us for about two weeks and wasn't quite attached to us, yet. The side effects this day were bad. I was exhausted, depressed and sick. At one point I put my head in my hands to cry, for no real reason, of course. At that moment, with no urging, Curry jumped onto the sofa, moved in parallel against my right leg and stayed there. He didn't move unless I did for the rest of the night, at least until my wife came home. That act cemented my little buddy into my heart. He hasn't done this since that night.



SURPRISE

My determination and insistence on improving my health continues to encourage my doctors. The growth in my abdomen has actually shrunk a bit, and I now change a 12 mcg/72 hour Fentanyl patch after 96 and have gone as far as 117 hours with no ill effects. I started in 2007 with a 25 mcg patch. My Testosterone, with the help of a testosterone gel, has leveled off and my eyesight has actually improved to about 20/25. One of the MD's was honest with me, actually to show his encouragement, and admitted that he didn't think I'd last more than a year or two after viewing my images. He enjoys seeing me come through his door, now. The growths otherwise have been stable for nearly two years.

FIN

How does the story end? Happily, I pray. With God and all who support and love me on my side, how can I lose? But, He has taught me a wonderful lesson through this trial. He's shown me that I'm not sick. I'm blessed. I've been given a way, fighting through fear and illness then arriving at prayer and determination, for Him to reach through me and help others who've received a frightening diagnosis. It can be seen as a brand new purpose for life, showing others that we are never alone in any fight. God, my wife, our family and our church, to name a few, have shown me one thing without a doubt. I will leave this Earth knowing I am loved. But, I have no plans to leave any time soon.

Walter W. Comer

Diagnosed in July of 2007.

Celebrating 50 years of wonderful life in May of 2011.

Celebrating, also, 12 fantastic years of wedded bliss in March of 2011.

More can be learned about ECD at erdheim-chester.org and I have a blog at

<http://walter327-goodintentions.blogspot.com/> and

<http://www.facebook.com/groups/241550579217632/>.



March 27, 1999