

Walking with Hope

Story by Hugh Welborn, ECD Patient Since 2015



My name is Hugh Welborn. I have been married to my wife Linda for nearly 35 years, and we have two adult sons. I am now a retired attorney and judge. Linda is a retired school teacher and college professor. For exercise I walked about four miles every day, rain, snow, or shine. I was in great health and felt great - until I didn't.

About five years ago, I started getting short winded and knew something was wrong. After getting a heart exam, the doctors told me I had two severe blockages. I had open heart surgery. However, I never got much better over the next year. I went to doctor after doctor, but I kept getting worse. It got so bad that I couldn't walk two steps without getting out of breath. I developed an odd cough that wouldn't stop at times. I couldn't sleep lying down, so I tried to sleep sitting up in a cushioned chair. **I had no relief and was miserable. Finally, I had a heart attack.** An MRI showed a foamy substance covering my entire body and squeezing a heart artery, which caused the attack. **No doctor at the hospital had a clue** what this foamy substance was, but a new doctor suggested that I go to the medical university in Charleston. There, the doctors performed a biopsy and one doctor had studied Erdheim-Chester Disease (ECD), and he determined I had ECD.

I studied everything I could about ECD and **thought I had a death sentence coming very soon.** I got my affairs in order, retired from the bench and had a great doctor friend of mine refer me to MD Anderson Cancer Center (MDA) in Houston. I also called the ECD Global Alliance (ECDGA) and personally spoke with Kathleen Brewer late one night. She had the patience of Job and a kind demeanor. **I now had hope!** After two trips to MDA, the doctors prescribed Mekinist (trametinib). In two days, I could breathe again! It was literally a miracle!

I now take Tafinlar (dabrafenib capsules) along with Mekinist. Although I am still retired, I do some pro bono legal work for the Family Court and help abused women in the courts for free as well. I am now back to walking every day, although not as fast or as far. I suffer from fatigue every day and take naps to get rid of it and my balance is impaired. I am going to Duke Medical Center since it is so much closer and they now have a program for ECD.

The ECD diagnosis was very scary, and I nearly died while the doctors tried to find out what I had. **I now appreciate life so much more, knowing how close I was to dying.** Honestly, it has changed my life for the better and I am so glad to be able to help others in my pro bono court work. Finally, thank God for Kathy Brewer and the ECDGA, because I know I am far from being alone in my walk with the diagnosis.