Ben Owens, 43

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October, 2019, first symptom;
September, 2022, diagnosed

BRAF V600e

ERDHEIM-CHESTER DISEASE
ECD
GLOBAL ALLIANCE

What Gives me Hope…

My family gives me a lot of emotional support with ECD and the accommodations I need. My response to treatment brings me a lot of hope, as when I first received Zelboraf, I felt immediately better. Along with the research being conducted on a rare disease.

Who am I?

Elizabeth & I were born on the same day, were married the week after I graduated from West Point & have been married for 20 years. We have 3 children, we enjoy keeping up with their sports; Benjamin Jr (15) just finished his senior year of football, Natalie (15) who plays year round soccer, & Matthew (12) who plays football, baseball, and wrestling.

My Diagnostic Journey

In Oct 2019, I was doing yardwork, when I reached to pick something up and got an odd numbness in my right arm. Later tha year, my first brain MRI showed significant lesions, but I was unique as I don’t have any of the other ‘typical’ ECD symptoms. 3 years later, after 14 MRIs, 100’s of vials of blood, and a brain biopsy I was diagnosed with ECD.

My Treatments

I started Zelboraf in Oct of 2022. It greatly reduced my brain lesions, immediately helped with my muscles, and significantly reduce my spasms, that were beginning to overtake me. I still struggle with spasms, balance, mood, and concentration. I’m going to be starting Cotellic soon to see if I can tolerate it better.

How I’m Doing

I’m fortunate I’m able to continue working. I find ways to still be active that don’t require as much balance. For example, I do a lot of stationary biking now. I struggle with getting sick a lot, which causes my symptoms to really act up.