



Edith Watters, 58

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August 2015, first symptom;
April 2016, diagnosed

BRAF V600e

What Gives me Hope...

The kindness of others has made a huge difference in my life. From the doctors who continue with research, give up their time to come and share at these meetings, the ECDGA providing answers and hope, my family who are constantly concerned and helpful, friends who always look out for me, to random strangers who help me get around.

Who Am I?

I am a retired special education consultant from Ontario, Canada. I am married mother of 26-year-old twins (a girl, Avery and a boy, Cameron). This is our 5th ECD Patient & Family Gathering.

My Diagnostic Journey

I saw a neurologist in 2015 who said, “don’t worry, we will get to the bottom of this.” I underwent a number of tests. The radiologist who looked at the bone scan thought it might be ECD. I was sent to a hematologist at Princess Margaret Hospital in Toronto who specializes in rare cases. It was after a femur biopsy that I was diagnosed with ECD.

My Treatments

I started with interferon for 8 months that didn’t do much. I then had a cycle of cladribine to bridge getting vemurafenib. I was on vemurafenib for 5 years. I went to see Dr. Diamond in NYC in 2022 and was switched to dabrafenib (150 mg) and trametinib (2 mg) daily due to CNS progression. I’ve been on dabrafenib/trametinib since.

How I’m Doing

I’ve been ok, but my walking and balance are still impaired. My doctors think that my speech has improved since starting my new treatment. I walk with a walker because I recently fell and broke my pelvic bone. I recently returned from a 2-week trip to Thailand, proving that with the correct supports in place, I can still do the things I love.