



Rebecca Winthrop, 64

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April 2014, first symptom;
August 2020, diagnosed

Incidental mutations, STAT 5A (CMML)

What Gives me Hope...

My family is extremely supportive. I have good neighbors where I live and I am hopeful that we can stay on the farm for several more years. My farm animals and the daily farm care routine keep me active and involved. I walk with our dogs nearly every morning.

Who am I?

Retired military officer. Married with two daughters, two granddaughters, and one great-grandson. Have spent the last 15 years running a little hobby farm in North Centra Florida just outside Gainesville. Vegan since October 2019.

My Diagnostic Journey

Thought I had carbon monoxide poisoning. Abnormal imaging Mar 2019. Referred to Mayo Clinic Jacksonville, FL Dec 2019. Brain biopsy, two bone biopsies, lumbar punch, etc. Positive ECD diagnosis Aug

My Treatments

Cladribine chemo infusion Oct, Nov, Dec 2020. Only 3 cycles completed of 6 planned due to pseudoprogression – all involved thought chemo made ECD worse – it did, but only in the short run. Months later lesions were breaking up. Recent PET/CT MRI imaging 2 yrs 8 mos following last cycle of chemo, no active disease progression - lots of scars.

How I'm Doing

All symptoms I had prior to chemo are still present. But no disease progression. Once live/ healthy brain tissue has been replaced with scarring. #1 complaint is fatigue, #2 is balance/dizziness, #3 is double vision at peripheral. Diabetes insipidus managed with desmopressin. I still manage the hobby farm with the help of my husband.