

Barry Atnip, 57

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August 2018, first symptom; January 2021, diagnosed

BRAF V600e

What Gives me Hope...

Hope springs from the dedication of doctors tackling my condition and the collaborative spirit among my medical team, all committed to understanding ECD. Their efforts, coupled with positive treatment responses, fill me with gratitude. Additionally, the support from the ECDGA and our community uplifts my spirits, reinforcing the belief and progress and a brighter future.



Who am I?

Married for 31 years with 2 sons. VP of operations at a family food brokerage for 34 years. University of Utah grad in economics, a former college water polo player. Enjoys skiing, hiking, friends/family time, and shopping at Home Depot, Costco, and Sam's Club. Loves listening to music and travel.

My Diagnostic Journey

First kidney biopsy at UCI/UCLA. Tumor board suggested a second kidney biopsy, confirmed by UCI/UCLA. Final diagnosis by Dr Beth Martin of Stanford for certainty. Experienced anxiety, fear, uncertainty, and sadness throughout the process.

My Treatments

Currently on Tafinlar/Mekinist, desmopressin for DI, and testosterone. Under the care of Dr. Diamond at MSK in NY, with local Southern California support form physicians at UCI, St. Jude/Providence, and a dermatologist. Challenges include managing multiple medications, hormone levels, and coordinating care among multiple doctors.

How I'm Doing

Physically, I maintain a full-time work and engage in activities like weightlifting, hiking, walking, and skiing. Emotionally, managing occasional anxiety is eased by providing for my family and enjoying social activities with loved ones. Overall, balancing work, physical activities, and social interactions contribute to my well-being.