

# Climbing for the Cure

*Family and friends gather on Father's Day to reach new heights for research on rare cancer.*

The Atnip Family completed our 5K this Father's Day. We had a nice day celebrating my husband, Barry Atnip (55) not only as a father to our two sons, Richard (25) and Bradley (20) but also for his tenacity towards fighting ECD.

Just a little back story on my husband...he was a high school and college water polo player as well as a lifeguard and swim instructor. After college, Barry began working for the family business and once our boys were born and old enough, began coaching baseball and water polo for over 12 years. He retired from coaching once the boys finished high school.

Two years ago, Barry was diagnosed with diabetes insipidus (during his last year of coaching). He managed this and all seemed fine until April 2020. **Barry became extremely fatigued and had several signs that something was wrong.**

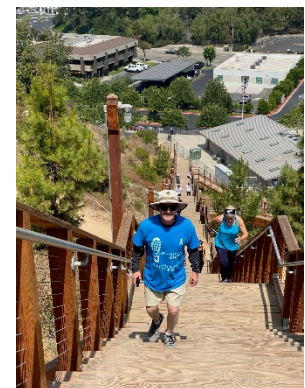


*Melinda, Bradley, Barry, Richard are ready for the family run.*

This past year, along with the challenges that we faced during the COVID-19 pandemic, we were thrown into an arduous 9-month journey to find a diagnosis for Barry's condition. It began with Barry's eye irritation and abdominal pain. What we thought was just some optical sun damage and a possible diverticulitis attack became something much bigger. For over six months, doctors thought he had lymphoma or sarcoma. **From April 2020 until now, Barry has had over twenty Zoom doctor appointments, seventeen face-to-face doctor appointments, and twenty different doctors (six eye specialists).** All physicians were from four various medical centers (St. Jude, UCI, Stanford, Memorial Sloan Kettering of New York City). He has had one CT scan, four MRI's, two PET scans, two biopsies of the abdominal mass behind his kidneys, one bone marrow biopsy, two echocardiograms, tumor genomic profiling, one set of X-rays (whoop-de-doo), three covid tests (one of which was positive, mild symptoms and fourteen days in the house), two root canals (unrelated but no fun), one crown and over one hundred fifty vials of blood were drawn.

Barry was diagnosed with Erdheim-Chester Disease on January 19, 2021. Barry finally began treatment on April 1, 2021. He is on BRAF and MEK inhibitors. **The good news is that Barry is finally feeling better!!!** Barry is working, exercising, skiing, mountain bike riding, and is hopeful about stopping the growth of his disease. We live each day with intention and are blessed to have our family and friends in our lives. Without the research and clinical trials conducted before 2016, treatment plans for ECD were scarce as you know. **We are thankful for the patients before us that have done the hard work to allow Barry to have the proper medication to treat this rare disease.**

So...at Coach Barry's request, during the ECD 5K, our family had to do a "stair climbing challenge." We started out on the nice leisurely trail in our city of Fullerton, then went to the "stairs." Barry requested that we all do the stairs, four times! Up one flight normally, then progressively building up to skipping the steps to the top. We ended our walk by the fountain at our local park. I was not happy skipping up he steps.



Although we are just beginning our Erdheim-Chester Disease journey, it is important to us to raise awareness and contribute to finding a cure. One step forward for Team Atnip, one step closer to a cure!

*By Melinda Atnip*