



Our names are Carolyn and Alex Finocchiaro, and we are a Mother/Daughter duo running the Boston Marathon this year on the Running for Rare Team. We have been running together for 6 or so years, and it has been an amazing way to bond and form a strong relationship. It is a time free from cell phones and the usual chaos of life. We have run multiple half marathons, and participate every year in the Boilermaker, a 15k in Utica NY.

So, why a marathon? And why Running for Rare?

Alex is a senior in high school, and each student must complete a senior project. This can pretty much be anything they want to do, some past projects of students included raising a duck, training a bunny, and fundraising for various causes.

Alex decided to do her project on how she can use her love of running to help people in the community, while also exploring how to train for and complete a marathon. Carolyn is a case manager at Sanofi Genzyme, working with Lysosomal Storage Disorders in the rare disease space. They found out about this group via her job. It seemed like a perfect fit for her project. And of course, Mom would have to complete the Boston Marathon if her daughter did, so here we are! Carolyn and Alex both were found to have Lynch Syndrome about 10 years ago due to multiple deaths in the family from various cancers. Lynch is a genetic predisposition to multiple cancers, but predominantly colon, ovarian, and skin. Carolyn has had a sebaceous carcinoma removed already. Screening and prevention are the major issues with Lynch, and we are both proactive in that regard. We have ties to the rare disease community through Lynch Syndrome and Carolyn's job working with Rare Disease patients. We have been partnered with a young boy with Aarskog-Scott Disease, and a young lady with MPS1.

We are extremely happy to be part of this team, supporting those with rare diseases, using our love of running to help a greater cause."

We are so excited to have you both on this year's team!