February 16, 2018

Hello from the Beraneks…

The 13th Annual Ultramini Triathlon is just around the corner. We are writing to you today to ask if you would consider making a tax-deductible donation to Foundation for Nager and Miller Syndromes (FNMS) as part of our event to raise money for FNMS. Our son, Saul, has Nager Syndrome and, we've chosen to celebrate his birthday each year by helping out FNMS.

Last year, we had around 100 people participate in our ultra-mini triathlon and 5K run. This year, the events will take place on the morning of June 9th in Marathon. We've enclosed information on sponsorship levels for you to consider.

Nager Syndrome is a very rare syndrome. People with Nager Syndrome have craniofacial differences, arm and hand deformities, and sometimes internal birth defects as well. These differences often lead to difficulties in breathing, eating, speech, hearing, and accomplishing tasks requiring the use of the arms or hands. Surgeries and therapies are a regular part of the lives of people with Nager Syndrome.

For many families living with Nager Syndrome, FNMS has been a major source of information and support. For us, FNMS was integral in our learning to cope with Saul's diagnosis. With the rarity of this syndrome, many of Saul's doctors relied on FNMS to learn about Nager Syndrome. FNMS also serves as a link between families that are affected by these extremely rare syndromes. Through FNMS, we have been able to communicate with families who are experiencing some of the same situations we are. One of the most important things FNMS does is organize a bi-annual family conference where families can actually meet, share with, and learn from other families living with these syndromes. Experts are also on hand to share their knowledge and the latest advances in caring for people with these syndromes. Last year in June, our family travelled to Boston and participated in this conference. It was the best-attended conference to date. Due to the money raised through charity DNA experts were able to come from Canada and children and adults with Nager and Miller syndromes were able for the first time to participate in genome sequencing. This vital project may help lead to new research for both syndromes as well as provide families with vital answers. This could not have been done without the vital financial support we get from our sponsors.

The best part of the conference is watching the kids just be kids because they feel safe and no one is staring or judging them on their appearance. In our opinion, FNMS is the most valuable resource available to people with Nager or Miller Syndromes.

We hope you'll consider supporting FNMS.

Sincerely,

Lara and Dave Beranek