

# Faces of Mito



## OCEAN AND AZALEA'S STORY

Today, you can find Ocean, an adventurous young boy spending his summer days sailing on a lake and his winters playing hockey with his friends in the local minor hockey league. Azalea, a bright girl, will give you a run for your money with her "Cheer Attitude" doing flips and being tossed in the air without a care in the world! It was not always this easy for these two and it certainly was not always without trouble. You would never have guessed that Ocean and Azalea spent the better part of their early years in and out of the hospital undergoing multiple hospitalizations and a battery of tests to figure out exactly what was wrong with them.

It all started one morning when Ocean's parents discovered him unconscious in his bed at the age of two and a half. He was rushed to the Montreal Children's Hospital where they discovered he had very low blood sugar and Ketoacidosis (a life-threatening problem that affects people with diabetes). These episodes slowly took hold of their daily lives and they were once again hit with a curveball when a few months later, Azalea started showing the same symptoms. Ocean and Azalea were quickly referred to Genetics. It had become evident there was an urgent need to find out what was wrong. Ocean had stopped gaining weight and did not have as much exercise tolerance as kids his age, and his parents feared the same fate for Azalea.

After ruling out the most common illnesses that could cause these symptoms, the family was approved for whole exome sequencing. The end-to-end process from "Day 1 of Symptom onset" to "Diagnosis" took over three and one-half years. Both Ocean and Azalea were diagnosed with a de novo mutation which causes [mitochondrial complex III deficiency](#). Subsequently, this opened a door to other people in their extended family getting tested (including their mother) who received the same diagnosis. The family was historically riddled with unexplained medical problems but were now given answers. As a result of Ocean and Azalea's medical journey, nine adults and one child within the extended family were identified with this mutation and able to receive the diagnosis and medical attention needed.

Ocean is now nearly 12 years old and Azalea is 9 years old. Symptoms of their mitochondrial disease have changed tremendously from what they were in the past and new challenges present themselves often. Ocean, Azalea, and their family are truly thankful to be surrounded by an incredible community of support like MitoCanada. The doctors at the Montreal Children's hospital have become a second family, and the family has an immeasurable sense of comfort in knowing they are surrounded by incredible care and support.

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