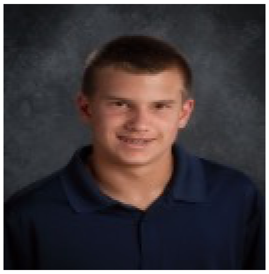
Michael Malecha

Diagnosed with LHON on August 25, 2014



What is LHON

Leber Hereditary Optic Neuropathy (LHON) is a rare mitochondrial disease genetically passed down by the mother.

The mitochondria that have a mutation can, at some point in time, function improperly to produce less adenosine triphosphate (ATP) (this is the high-energy molecule that stores the energy we need to do just about everything we do) and more Reactive Oxygen Species (ROS), causing the cells in the optic nerve to die off.

Male carriers have a 50/50 chance of becoming affected, and female carriers have an 8% chance

Males usually become affected between the ages of 15 to 25, and females at menopause.

From initial vision change to central blindness, it usually takes 6 to 8 weeks. 96% of those affected carry one of the 3 major mutations: 11778, 14484, and 3460.

Most doctors have no clue what LHON is.

My Journey

On August 20, 2014, I went for a physical and was asked to do the eye chart. My right eye was 20/15, and I couldn't see the eye chart with my left eye. My mom thought I needed glasses. The next day, I went to the eye doctor and found out I didn't have central vision in my left eye. The eye doctor sent me to a retinal specialist. They made an appointment with a neuro-ophthalmologist at the U of M on August 25, 2014. He ran some tests and looked at my parents and me and said, “I believe you have a disease called Leber Hereditary Optic Neuropathy and you will most likely be centrally blind in 6 to 8 weeks.”

In October, we received the news that I tested negative for the 3 major mutations of LHON. My vision hadn't changed, and the Dr. at the University of Minnesota decided that maybe I had a virus that was causing my central vision to go, but it was lurking in the back of our minds. I have a 4% chance of having an odd mutation. Life went on until the 1st week of March 2015, when my right eye (my so-called good eye) began to show signs of black spots.

Back to the University of Minnesota we went, and there were signs that the optic nerve in my right eye was swelling. A full Mitochondrial DNA test was done. On June 5, 2015, our last day of school, the results came showing that I carry a rare genetic mutation with the number 3890, and there have only been a few people in the whole world with the same mutation.

LHON Conference 2015

On June 15, 2015, my mom and I went to a conference on LHON in Washington, DC. We met 33 people who have the same eye disease. All were affected with one of the 3 major mutations. I felt like I was the only one who had an odd mutation. Each of us had our own story and journey. The age ranged from people in their 70's down to 14. Men and women both. This was a wonderful experience for both my mom and me. We met 3 research doctors, and they are working on trying to find a cure. One doctor is from the US.

Others I met affected with LHON in Washington, DC

What I See Today

As of right now, I am considered legally blind. My vision in both eyes is 20/250. This doesn't mean I cannot see it; it just means my vision is very bad. I am no longer able to drive. When crossing streets, I cannot see if the stoplight is telling me to walk or not. At this point in time, the font size I can read is 26 bold, but it is slow going. This also depends on the day. Some days are better than others, meaning my vision is constantly changing.

A normal person without LHON would see like this on the left, and on the right is what a person with LHON sees:


Healthy Vision


LHON Vision

Right now, I can see your face when we are standing and talking. I can see whether your eyes are open or closed, and whether you have glasses. I cannot tell what color your eyes are. That is from a distance of 5 ft.

What I Need Help with in School

I cannot see the board or what you are doing in detail beyond 2 feet in front of me. When I read, I have to hold items close to my face.

I use a magnifier on my cell phone or a Ruby magnifier.

At school, I am using a VisioBook with a camera so I can see what you are doing on the board and the worksheets you hand out.

I use my Apple computer with VoiceOver and the magnifier to complete my work.

At home, I have a CCTV which is like my VisioBook but on a larger scale.

Please be patient with me as I am having to relearn everything that has been taught to me over the past 11 years with vision, and now doing it with limited vision. I have to learn new technology, listen to books instead of reading, and work on my short-term memory.

I am willing and most certainly able to learn.