

LEAP Award

LEAP stands for Living, Encouraging, Achieving and Persisting. The award is presented to an individual who is age 14 or older living positively with mitochondrial disease. The Awardee overcomes daily challenges to achieve goals in career, family, and volunteer service. The individual demonstrates a positive attitude, hope for a brighter future, and an enthusiasm that inspires others.

The 2017 LEAP Award Winner is **Michael Malecha**, from Northfield, MN. During a routine physical in 2015, Michael's doctor and family noticed some vision problems. Within five days, doctors were giving Michael and his family the diagnosis of LHON and would be centrally blind in 6 - 8 weeks. Imagine the devastation to anyone, any family. Michael was looking forward to driving, and in growing up on a Minnesota farm, all of the increased responsibility and help that he could provide to his family's farm operation. All of that now seemed lost.

But Michael and his family decided to stay positive and make a difference. They found the best care for Michael. They found the resources to have assistive technology for Michael's schoolwork. He began to learn Braille and orientation mobility. The family attended the UMDF symposiums where Michael participated on a teen panel and participated and fundraised for the Minnesota Energy for Life Walk. In 2016, the Malecha family organized a "Dinner in the Dark" fundraiser that raised nearly \$40,000 for the LHON project fund. This year, Michael has signed on as an UMDF Youth Ambassador, with its mission to inspire and educate others about mitochondrial disease.

Each month, Michael finds & schedules an opportunity to speak to local youth, his peers and adults about his life experience of facing blindness, about his journey, struggles and fears. He has spoken to his classmates, church groups, & civic groups, along with giving the keynote speech at "Dinner in the Dark". Michael attends the Minnesota support group meetings to connect with other kids and teens with mito as well. Another mom at these meetings said of Michael "I am so amazed by Michael. I met him a couple of summers ago and since then I have watched him become a role model to other mito warriors. My son Nathan looks up to him. He has taken his diagnosed in stride and he wants to help other. He is so amazing."

Through all of his struggles, Michael has continued Living, Encouraging, Achieving & Persisting - **AND**, the most miraculous and positive part of Michael's story is that in August of 2016, Michael's vision went from 20/450 back to 20/20 with central scotomas. He and his family don't know if the vision will stay, but they most certainly won't take it for granted.