



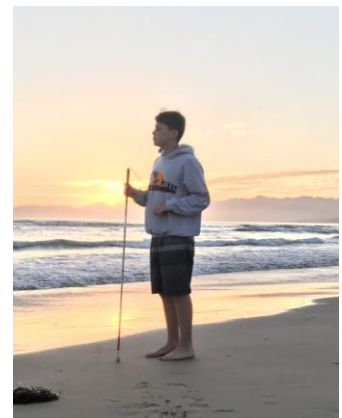
4th Annual Anthony's Seeing is Believing Pismo Beach 5k Walk/Run on the Beach September 14, 2019

We cannot believe we are planning our 4th annual Anthony's Seeing Is Believing 5k Walk-Run in Pismo Beach. My wife Karrie, and myself Tony Ingram, along with our family and friends started Anthony's Seeing is Believing Foundation in 2012. February 2012, we had our first run in Bakersfield, CA (where we lived at the time) and continued to have our event there until February 2018. Our family moved to the central coast in 2014 and started our 5k run here in Pismo Beach in 2016. With many runners coming over from Bakersfield, we decided to combine both events and have one event in Pismo every September. Our goal is to raise awareness about blindness and raise money to help fund research for LCA (Leber's Congenital Amaurosis). We have hope that researchers will find a cure for LCA and will one day, be able to give our son Anthony sight. Many have followed our journey for years. We have been blessed with all who have helped and supported us.

Our journey started when our son Anthony was just 3 1/2 months old and was diagnosed with LCA. We were devastated to hear the diagnosis that our son was blind. We've always had our faith & strong support from our family and friends. We took our initial feelings of devastation and focused our energy towards the positive. We



were determined to tackle the disease "head on" and provide Anthony with all of the tools he would need to succeed. We have raised Anthony the same way as our two older children, Kiley age 16 and Katie age 15. From the very beginning Anthony has had a strong personality and has been very persistent. Anthony doesn't let any challenge stand in his way and he is always ready to try anything new. He's always been as comfortable on the playground, in the swimming pool or climbing trees as any sighted child. Anthony reads Braille and is aided with a white cane for mobility. He has been "mainstreamed" since kindergarten in the same public schools as his sisters. Most people that meet Anthony don't believe



he is blind because his is so active and outgoing. Anthony has participated in the Junior Blind Olympics in Los Angeles and earned 5 medals. Anthony has played organized teams sports such as soccer, basketball, T-ball as well as taking Jiu Jitsu lessons for 4 years. Anthony is truly an inspiration. For Anthony, everything is a learning experience.

Anthony update: Anthony is 14 years old and is in 8th grade at Judkins Middle School. This year Anthony was the student body treasurer at his school. He also started playing drums and played during VBS at church. At home he can often be found building with Legos, playing with model trains, playing his piano or drums and singing. Some of his favorites outside activities are hanging out at the beach, boogie boarding, surfing, paddle boarding, kayaking and hiking. Since he could walk he's been out in the garage helping his dad with metal and woodworking projects or working on their antique Mack trucks. He has learned all of the mechanics' hand tools by feel as well as using power tools. Not a day goes by where there's not a smile on his face, as he looks towards the sun, and has a skip in his step as he runs his way through life.

What is LCA? Leber's Congenital Amaurosis (LCA) is a very rare, genetic hereditary disorder that causes severe vision loss and blindness in infants and children. Of all the retinal degenerations, LCA has the earliest age of onset and can be the most severe. There is no known cure for LCA. Anthony suffers from a mutation in the CRX gene, which is the rarest of the 20 known genes. CRX mutation comprises only 1%-3% of the 3,000 cases of LCA in the US.

What treatment is available? Clinical trials of gene replacement therapy for LCA caused by mutations in the RPE65 are now underway at Children's Hospital of Philadelphia, Universities of Pennsylvania, Florida and Moorfields Eye Hospital at the University College of London.

Children and young adults who were nearly blind have had dramatic improvements in their vision after treatment. This is the same therapy that gave vision to 60 dogs, including the world famous Lancelot, born blind from LCA caused by genetic variations.

In October 2017 the FDA's Cellular Tissue and Gene Therapies Advisory Committee unanimously voted to recommend "Spark Therapeutics' Luxterna" for regulatory approval. "The vote validates gene therapy as a viable treatment", Dr. Yoo said. This will be the first time that a genetic therapy has been used to treat an inherited disease in the United States.

We have been in direct contact with doctors that are conducting research on Anthony's gene mutation, LCA-CRX and are hoping to have exciting news to share from them soon. This is a very critical and exciting time with regards to LCA research and with events like ours helping to fund research and trials, a cure may come sooner than we think!

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Check out our webpage www.anthonysseeingisbelieving.com or look up our Facebook page **Anthony's Seeing Is Believing**.

If you have any questions please contact us.

Thank you,

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Anthony's Parents
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anthonysseeingisbelieving@gmail.com

**Anthony's Seeing Is Believing Pismo Beach
5k Walk/Run on the Beach
September 14, 2019**

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