SOFIA SEES HOPE

Supporting the LCA and rare retinal disease community.
We see a cure for blindness.

SEEING HOPE | Newsletter

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April 2018 | Issue 3

From the Founder

It took more than seven years to get a genetic diagnosis for our daughter. During that time, doctors were pretty sure she had LCA, although we also heard that maybe she had cone-rod dystrophy or perhaps Stargardt disease. We argued with insurance, paid out-of-pocket, took time off work and school for trips out of state and sent blood work all over. Still, no one could give us a genetic diagnosis. Some labs never even bothered to return phone calls to tell us if they had any results.

Sofia Priebe & Laura Manfre

And then things changed. More genes had been identified and there were new and better ways of genetically diagnosing IRDs. Finally, in 2013, we received a confirmed diagnosis for Sofia.

Flash forward another 5 years to today and there are even more changes. While many aspects of obtaining a genetic diagnosis are still challenging, thanks to continued research, increased awareness, and accessible testing programs, it's no longer a seven-year ordeal. Patients can get tested today without incurring travel expense and are much more likely to receive a confirmed genetic diagnosis.

Thanks to donations to our organization, we have been able to support accessible genetic testing for families. Thanks to our donors and supporters, we are also able to provide outreach and education

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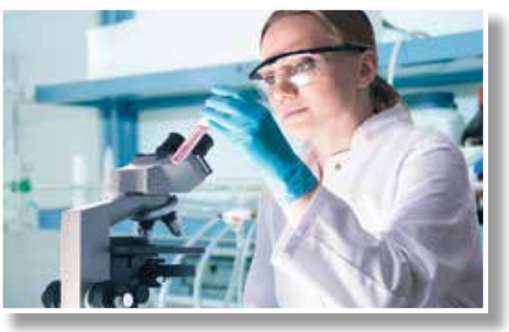
SSH Donates $65K to Help Ensure Free Genetic Testing for IRD Patients

Support is part of SSH's '#KnowYourGene' Campaign for 2018

By Elissa Bass



Sofia Sees Hope is helping to ensure that inherited retinal disease patients have access to critical genetic testing through its financial support of a Foundation Fighting Blindness program.

In December 2017, SSH donated $65,000 to FFB's free genetic testing program, which gives qualified individuals access to free genetic testing and counseling. It was the organization's second donation to the program, having provided $15,000 to support a test run of the program in January 2017.

Dr. Brian Mansfield, FFB's deputy research officer who manages FFB's patient registry, My Retina Tracker (MRT) and the genetic testing program, said that SSH's initial $15,000 donation and other funding led to testing approximately 600 samples in 2017. With the increase in funding, that number can grow exponentially.

Sofia Sees Hope could make this latest donation because of its successful fundraising in 2017, primarily through its signature gala event, Dinner in the Dark, as well as individual contributions to the organization throughout the year.

"Last year, we were excited to support the test program and we couldn't be more pleased with the outcome," said SSH co-founder and Board of Directors chair Laura Manfre. "This year, thanks to the tremendous support of our donors, we were able to more than quadruple our contribution as the program expands, enabling many more individuals with rare IRDs to receive free testing and genetic counseling."

With inherited retinal diseases, genetic testing is needed to confirm a clinical diagnosis. With some IRDs, including Leber congenital amaurosis (LCA), myriad genes can cause the disease. Pinpointing the specific gene helps patients find the best and most appropriate

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Ready To Live Without LCA

By Rosanne Smyle

When Creed Pettit turned 9 on January 9, his birthday wish was that it be the last one he celebrate with vision loss. On March 21, Creed's wish began to come true, when he started gene therapy treatment with LUXTURNA™.

Creed was diagnosed with Leber congenital amaurosis when he was almost 3, although his mom, Sarah St. Pierre Pettit knew something was wrong with her baby shortly after he was born in 2009.

"He missed all of the milestones. He would run into everything. He wasn't walking. Instead, he did this weird Army crawl. He'd feel for his food and look up. Everything just said something's not right."

The path to diagnosis was fraught with heartache. First, doctors diagnosed Creed at 18 months old with autism. Another said he had problems with his peripheral vision. Sarah finally found a woman specializing in depth perception and dyslexia. For the first time, and coming from a non-doctor, Sarah learned that her son probably was blind.

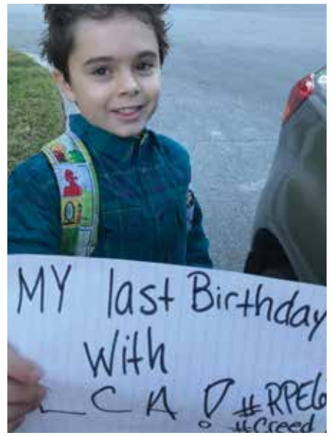
In 2011, doctors diagnosed Creed with LCA; in the months following he received a genetic diagnosis of LCA-RPE65. Sarah created a team for her son of therapists and specialists to address Creed's movement, vision, speech, orientation, mobility and behavior.

She learned about gene-therapy trials and she, her mother, and Creed traveled to Iowa twice for what turned out to be unsuccessful attempts to be part of the research. Creed could not perform steps required by the study, such as trying to navigate a maze.

It was in mid-February that Sarah learned her insurance company gave the go-ahead to schedule the surgery that costs $850,000. "No more hurdles," she wrote in an email. "I am a wreck of happy tears!!!"

Creed is having the procedure done at Miami's Bascom Palmer Eye Institute by Dr. Audina Berrocal.

People with LCA-RPE65 can't make a protein needed by the retina to convert light into vision-enabling signals, which are sent to the brain. This new therapy involves injecting a human-engineered virus containing copies of a normal gene under the retina, so cells can express the protein.



Creed on January 9, 2018 when he turned 9 years old.

Creed said that after the surgery, he can't wait to see a real rainbow and he can't wait to throw his canes in the lake.

Follow the progress on our website (www.sofiaseeshope.org) of Creed Pettit, a 9-year-old Florida third-grader who is undergoing gene-therapy with LUXTURNA™, to reverse his blindness caused by LCA-RPE65.

SSH Donates $65K For Free Genetic Testing

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treatments and clinical trials for possible cures. Additionally, some forms of LCA can include other health issues—such as kidney function—which are critical to uncover early.

Obtaining a genetic diagnosis for a rare IRD is complex, and this program managed by FFB makes testing and counseling accessible to those with a qualified clinical diagnosis. In addition to being free, families do not have to travel distances to special medical facilities or genetic counselors to take advantage of this specialized testing. The panel itself tests a broad spectrum of 181 genes across IRDs, including LCA, retinitis pigmentosa, Stargardt disease, Usher syndrome and more.

The FFB testing program expansion comes on the heels of the U.S. Food and Drug Administration's Dec. 19, 2017 approval of LUXTURNA™, the first gene therapy for a genetic disease in the United States. LUXTURNA™ restores sight in those with the RPE65 gene mutation, and underscores the importance for the patient community to undergo genetic testing.

"We now have our first treatment on the market for one genetic mutation of LCA, and we anticipate others will follow," Manfre said. "To continue to attract researchers and accelerate these treatments requires an identified and informed community, and that means making genetic diagnosis accessible.

"For a long time and still today, there are families and medical professionals who don't know where to go for this specialized testing, or are turned off by barriers of cost and travel," she continued. "This program eliminates those barriers. It is our job at Sofia Sees Hope to makes sure this program remains accessible not only with our financial contributions but also through our own education and awareness activities."

Events

DO YOU HAVE AN EVENT YOU WANT TO SHARE? LET US KNOW!
Email rosanne@sofiaseeshope.org with the information and a link.

Foundation Fighting Blindness Vision Seminar Series
April 21 • St. Louis, MO
www.blindness.org/conferences
The Foundation Fighting Blindness seminar series offers information on the latest research advancements, treatment options and clinical trials. Visit FFB's website for seminars as they are scheduled.

The 8th Global Orphan Drug Conference And Expo
Strategy, Regulation and Opportunity for Pharma, Biotech and Investors in Rare Diseases
April 25–27 • Gaylord National Harbor Hotel • Oxon Hill, MD
www.terrapinn.com/conference/world-orphan-drug-congress-usa
World Orphan Drug Congress USA focuses on the most pressing challenges and opportunities to bring rare disease therapies to patients faster. Join 1,000 leaders in orphan drugs from 38 countries, hear more than 135 presentations covering all aspects of orphan drug development and rare disease research.

The Association for Research in Vision and Ophthalmology
April 29–May 3 • Honolulu, HI
www.arvo.org/annual-meeting
At ARVO 2018, 11,000 international basic and clinical researchers will share the latest breakthroughs in vision research. Engage with your colleagues as we work to advance our science and expand its support within our communities and governments.

Global Genes RARE Patient Advocacy Summit
May 19 • Philadelphia, PA
globalgenes.org/2018raresymposium
Global Genes and the University of Pennsylvania Orphan Disease Center (ODC) third annual Patient Symposium, in conjunction with UPenn's Million Dollar Bike Ride (MDBR). The Symposium is for patient advocates to learn, connect and be inspired. Attendees do not need to be affiliated with the MDBR and all rare patients, advocates and stakeholders are welcome to attend!

Rare Disease Summer Family Camp 2018
May 31–June 3 • Ashford, CT
rarediseases.org/wp-content/uploads/2018/01/2018-Spring-Family-Weekend-Application.pdf
A Special Weekend for Families in the Rare Disease Community at The Hole in the Wall Gang Camp. This is a special Summer Family Camp for children and families impacted by rare diseases to join together for a weekend of pure fun—free of charge.

Global Genes and EveryLife Foundation for Rare Diseases
RARE on the Road Rare Disease Leadership Tours
June 9 • Houston, TX
June 30 • Salt Lake City, UT
July 21 • Nashville, TN
globalgenes.org/rotr2018/
RARE on the Road brings critical education and insights to rare disease patients, advocates and caregivers, while collaborating in an interactive, engaging environment. Topics include the Patients' Role and Drug Development, along with breakout sessions and hands-on workshops.

VISIONS 2018 National Conference
June 21–23 • San Diego, CA
www.blindness.org/visions
VISIONS, the national conference of the Foundation Fighting Blindness, is the only event of its kind—created solely for individuals and families who are affected by retinal diseases. Find access to information on the latest retinal research and clinical trials, the doctors performing the work, and other families from around the country living with the same diseases.

2018 Choroideremia Research Foundation Conference
June 21–24 • Dallas, TX
urechm.org/conferences
The Choroideremia Research Foundation conference offers multiple presentations by world renowned researchers and the latest scientific updates. Learn about treatments in the pipeline to gain a more in-depth understanding of CHM, and to connect with an amazing network of individuals and families who are also impacted by the disease.

From the Founder

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to families, which drives awareness and access for genetic testing and encouraging participation in natural history studies and patient registries.

Our awareness campaign this year is **Know Your Gene: Get Tested, Get Connected**. Knowledge is power and we are helping more families get tested so they can receive their genetic diagnosis and then connect in ways that will accelerate research for treatments and cures for IRDs. We want to stress the importance of connecting to a patient registry or a genetic counselor. We want to help families and individuals find each other for support and sharing of information. And we are driving those programs and communications that will continue to advance cures for blindness.

We know how important it is to know your gene. We've lived it.

Laura

In January 2014, Laura Manfre founded Sofia Sees Hope. The nonprofit funds the development of cures not just for her daughter Sofia's LCA gene, but also supports diagnosis, treatment and cures for all children and adults suffering from blindness caused by any of the 27 genes related to LCA.

Tell Us Your Story

A Precious Exercise of Mindfulness

By Claudia Zaghi-Biggs

When I met Brandon in September 2014, I thought that I was talking to the most interesting person I had ever met.

Not only was he the first American I had ever talked to, Brandon was also the opposite of the typical 20-something Italian: Not Catholic, vegetarian, mostly homeschooled, who preferred peanut butter over Nutella.

Besides the cultural diversities, I immediately liked his positive way of thinking, his unusual curiosity and his witty sense of humor.

Another particularity of Brandon was his blindness, which is actually the reason why we met.

I was giving a tour of my university, the University of Milano, Italy, for international students and I was asked to guide Brandon, who was there to study Italian for opera. Among a group of a hundred students, it would have been unlikely that I would have gotten to know any of them. Since Brandon was by my side, however, we had the chance to talk during the tour. And then we scheduled a date.

We were married two years later.

The last three years with Brandon have been quite a journey; we have been apart for several months, but we also managed to live in five countries and visit nine in total.

I have special memories for each of them, for example swimming in the crystal sea in Croatia for our honeymoon, walking through the Christmas markets in Vienna, visiting the Nobel Museum in Stockholm, making cheese on a Maltese farm, seeing "Matilda the Musical" in London. These are just a few of the unforgettable moments we have shared so far.

Currently, we are happily living on a houseboat on a little canal in the city of Groningen, Netherlands, where I am studying for my master's in computational linguistics.

I consider living with a blind partner a precious exercise of mindfulness. If I am alone, I walk in the street careful enough to be safe, but I am immersed in my thoughts, listening to music with my isolating headphones. When I am with Brandon, I acknowledge everything around me: people, buildings, colors, behaviors, my own emotions, and I feel that I am present in the moment.

At the same time, I acknowledge accessibility issues, which are a wide problem in south European countries. Sidewalks are too narrow, uneven or used for parking by cars. Also, street lights without sound effects or unsafe driving behaviors are a cause of frustration for me.

Brandon & Claudia

Previously I said that Brandon and I met because he was blind, which is not exactly the truth.

Brandon's education, O&M (Orientation & Mobility) training, and his (now, also my,) incredible family have made him an independent, healthy and positive person, confident enough to decide to take a plane solo, cross the ocean and live abroad for one year to learn a new language.

Therefore, I am forever grateful to everyone who contributed to Brandon's education. I am now happy to see Brandon helping his mum, Sonja, to build educational services that can have a significant impact on other young blind determined students.

Read more about Brandon Biggs and his family on our website, www.sofiaseeshope.org/resources/blog

SSH Provides Help Finding Others Like You

Sofia Sees Hope has launched a Family Connections program designed to help end the isolation that many feel when they receive a rare inherited retinal disease diagnosis.

The Family Connections program makes it easy for those with Leber congenital amaurosis (LCA) or another rare inherited retinal disease (IRD) to connect with another family or individual by phone or email. Being diagnosed (or having a family member diagnosed) with a disease classified as "rare" can be isolating and lonely. It makes you feel like there is no one else in your situation. This program is designed to alleviate those feelings.

Simply visit **sofiaseeshope.org/resources/connect** on our website and fill out the brief form on the page. Our Family Connections coordinator will reach out by phone to confirm your information and anything else you want to share. Then we'll provide you with the phone and/or email contact information for another LCA or IRD individual, family member or caregiver, and let you take it from there!

Please know that we take our privacy policy seriously. We make contact by phone with all of our families first, and we will only share your information with another LCA or IRD family or individual who has also given us permission to do so.

Therapy Development: A Long and Winding Road

The steps for getting a vision-saving treatment out to the people who need it

By Ben Shaberman, Director, Science Communications Foundation Fighting Blindness

The FDA's 2017 approval of Spark Therapeutics' LUXTURNA™ for people with RPE65 mutations causing Leber congenital amaurosis (LCA) and retinitis pigmentosa (RP) marked one of the greatest advancements ever made in treatment development for the eye. The groundbreaking, vision-restoring gene therapy was made possible by hundreds of the world's top retinal scientists working for more than two decades. The development team included investigators from: Children's Hospital of Philadelphia (CHOP), University of Pennsylvania, University of Florida, Cornell University, University Hospital Eppendorf (Germany), and the National Eye Institute (NEI).

A major challenge in getting LUXTURNA™ to the marketplace was that gene therapy was considered risky and cutting edge in the 1990s when Drs. Jean Bennett and Al Maguire first envisioned it as a treatment approach for inherited retinal diseases (IRD). Their pioneering work means that retinal gene-therapy development today, in many cases, is a less-daunting endeavor. And that is why FDA approval for LUXTURNA™ is such a huge boost for so many IRD patients—it has moved the retinal gene-therapy field forward in a huge way.

Using LUXTURNA™ as one example—and definitely not one that applies to all development efforts, especially those for other therapeutic modalities (e.g., stem cells)—here is a brief summary of the major (not all) research steps required to get an IRD treatment out to patients.

1) Understand the Disease, Why Vision is Lost

This initial step often involves understanding how a mutated gene leads to vision loss. When a gene is defective, it doesn't express enough protein, or it doesn't make the right protein. Does the missing or dysfunctional protein cause problems with photoreceptor development? Does it affect photoreceptor health and maintenance? Is it involved in light processing?

Researchers at the NEI first identified the RPE65 gene in 1993. However, they didn't figure out until 1997 that RPE65 mutations were linked to LCA caused by faulty vitamin A processing. When vitamin A is not properly metabolized, the retina can't process light.

2) Develop or Identify a Disease Model

Disease models are helpful in understanding how vision is lost (Step 1) and testing potential therapies (Step 4). In many cases, researchers will genetically engineer (knock out the gene in) a rodent so it develops the target IRD. Sometimes, models are created using cells in a dish.

In 1998–99, researchers were fortunate to identify a canine breed (briards) with naturally occurring RPE65 mutations causing LCA. This was an optimal model for therapy testing, because, unlike rodent eyes, the canine eye is similar in size and structure to the human eye.

3) Design and Produce the Therapy (for Lab Studies)

There are many considerations when designing any treatment. What is the ideal formulation? How should it be administered? Should multiple variations of the treatment be evaluated?

Designing a gene therapy is especially challenging. Developers need to determine several design elements, including: a) the type of human-engineered virus for gene delivery; b) the type of capsid (the shell of the virus); c) the promoter (the gas pedal for the virus); d) which type of cells to target; and e) where in the retina to inject the therapy. This list goes on. Design is often an iterative process in which these elements are tweaked during testing (Step 4).

The RPE65 gene therapy was delivered by an adeno-associated virus (AAV) via subretinal injection.

4) Test Treatment in Model

Testing is also often a time-intensive, iterative process in which the treatment is being re-designed and re-evaluated (Step 3) to come up with an optimal solution. Also, researchers need time to determine if the therapy is working and if the vision-saving or -restoring effect is sustained.

The great news for RPE65 gene therapy was that it worked well—the treatment bestowed vision to briards born blind. The dogs were treated in 2000 (estimated), and vision-restoration was sustained for the lifetime of the animals.

5) Translation: Advancing the Therapy into a Clinical Trial

Moving an emerging therapy out of the lab into a human study is risky and expensive, costing millions of dollars. Plus, the researchers/developers need to understand how to design a clinical trial and gain authorization to launch it from the FDA (or another regulatory agency—e.g., EMA in Europe). Launching a human study requires specialized expertise. Furthermore, the therapy for the study must be produced in a facility that uses good manufacturing practices (GMP), which mandate high standards for quality and safety.

CHOP had the resources (financial, technical) and expertise to conduct an RPE65 gene-therapy clinical trial. Given that gene therapy had such a limited clinical track record, it took CHOP about six years to design the study and gain FDA authorization to launch it. Ultimately, it needed to spin-off a company, Spark Therapeutics, to raise money to move the treatment through the later stage (Phase 3) of the trial and apply for marketing approval from the FDA.

6) The Clinical Trial

A typical clinical trial will last seven to 10 years. The cost is $40 million to $50 million minimum, and usually much higher (hundreds of millions of dollars). Trials usually have three phases: 1) safety-oriented, 2) early evaluation of efficacy and various doses, and 3) pivotal, multicenter. (Sometimes for an orphan treatment, the phases are combined.) If the treatment is successful in Phase 3, the developer will likely seek FDA approval to make the treatment available to all who can benefit from it.

The CHOP trial for what is now LUXTURNA™ began in late 2007. Phase 3 concluded in 2015. Overall, the treatment was safe and restored significant vision in participants (12 patients in Phase 1/2 and 31 patients in Phase 3.)

7) Application for FDA Approval

After what appears to be a successful clinical trial, the developer will submit an application—a new drug application (NDA) for drugs or a biologic license application (BLA) for gene, stem-cell, or protein therapies—to the FDA. The process involves creation and submission of an enormous amount of documentation. It also involves much dialogue between the FDA and the therapy developer.

Additional Information

To learn more about the drug development and approval process, please visit www.fda.gov/drugs.

The Foundation Fighting Blindness (FFB) funded critical lab and clinical research that made LUXTURNA™ possible. Visit www.blindness.org for more information on FFB-funded research.

College Connection by Jack McCormick

Making A Successful Transition To College

Starting high school or going off to college is not easy; new people, classes and sometimes even a new city make for a stressful transition. Doing it all with a vision impairment adds some additional complexity. I am going to share with you my experience of moving to college with a vision impairment. Hopefully you can learn from my experiences and apply it to your own life.

Four years ago I knew that I wanted to attend Wilfrid Laurier University. When I received my acceptance letter, I immediately started to plan, which proved to be incredibly important. I was able to connect with various people at the university: getting a larger dorm room at no additional cost to accommodate my guide dog, speaking with the Accessible Learning Center to arrange exam accommodations (I write my exams on a computer in a private room), and connecting with professors before classes started.

For someone with vision loss it can be challenging to navigate a new place and college campuses are no different. It is so important to learn the layout of your college before move-in day because I am telling you, you won't have time during frosh week and you will want to know where your classes are before they start. There are a lot of benefits to knowing the layout of your campus beyond being able to find your classes and places to eat.

1. If you know where things are better than the people on your floor, then you can help them find their classes. It's a good way to get to know people and show them that you don't let your vision loss stand in your way.

2. Getting involved with campus organizations is a great way to have some fun and get to know like-minded people. These organizations aren't going to meet in the same places as your classes. So you need to be able to find them or you are going to miss out on one of the best parts of college life!

Jack McCormick and his guide dog Jake, center, at a recent "Eye To Eye" event Jack organized at his college. On the left is Dr. Penny Hartin, CEO of the World Blind Union, the guest speaker at the event.

"So, Jack, I've planned and learned the layout of campus. What about the first day? How do I make friends? I am worried that people will judge me because of my vision impairment."

Remember that all people are nervous during their first days of college. You are not alone! Own your vision impairment, tell people about it and be open to answering questions (you will get some dumb ones). This eliminates any awkwardness that people may have about your vision loss and soon you will find a great group of friends!

I hope this helps as you move away to college!

Jack McCormick is a 21-year-old honors business student at Canada's Wilfrid Laurier University in Waterloo. Jack was diagnosed in high school with Leber congenital amaurosis due to mutations in the RPE65 gene. He is a Sofia Sees Hope ambassador, helping people living with LCA and IRDs. Read his blog at jackdamccormick.wordpress.com

Come visit us at VISIONS 2018!

Sofia Sees Hope will be in the exhibit hall, plus we're planning an after-hours get together for our LCA families. More information coming soon.

Drop Danielle a line at danielle@sofiaseeshope.org to let her know if we will see you there!

FOUNDATION FIGHTING BLINDNESS
VISIONS2018
LEARN. SHARE. EXPERIENCE. HOPE.

VISIONS 2018 National Conference
June 21–23 • San Diego, CA
www.blindness.org/visions
VISIONS, the national conference of the Foundation Fighting Blindness, is the only event of its kind—created solely for individuals and families who are affected by retinal diseases. Find access to information on the latest retinal research and clinical trials, the doctors performing the work, and other families from around the country living with the same diseases.

SAVE THE DATE!

SOFIA SEES HOPE — WE SEE A CURE FOR BLINDNESS.

DINNER IN THE DARK

An evening to benefit Sofia Sees Hope

Saturday, October 6, 2018
Mystic Marriott Hotel & Spa • Groton, CT

Visit www.sofiaseeshope.org for more info, tickets and sponsorships

PATIENT ADVOCACY

On Rare Disease Day, Shining A Light

By Rosanne Smyle

Lisa Kurec had never heard of the National Organization for Rare Disorders (NORD), but after many years of finding no answers for her son's illness, she decided to attend NORD's Rare Disease Day event on February 28 in Hartford, CT. On that day patients, families, caregivers, medical professionals, industry representatives, and legislators all gathered to help shine a light on these conditions.

Over the years Kurec, of Middletown, CT, took her son to 25 doctors, all unable to determine why he suffered from painful ulcers throughout his body. Some symptoms were even attributed to age-appropriate conditions, such as acne.

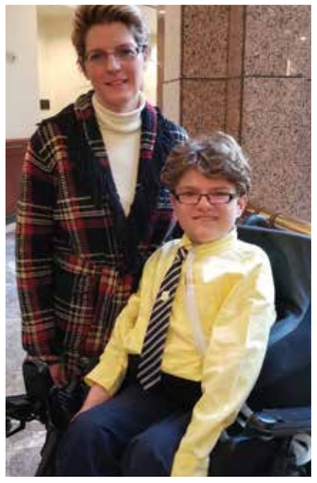
She finally took him to a dentist, who sent him to the emergency room, where he was referred to an infectious disease doctor. By 2014, her now 26-year-old son was diagnosed with Behcet's disease (pronounced beh-CHETS), a rare disorder that causes blood vessel inflammation throughout the body. Signs and symptoms seem unrelated at first, and include mouth sores, eye inflammation, skin rashes and lesions, and genital sores.

The Connecticut event was hosted by NORD, the official sponsor of Rare Disease Day in the United States, and NORD's Connecticut Rare Action Network. NORD President Peter Saltonstall told the gathering of about 120 people that there are about 7,000 rare diseases, with fewer than 500 having FDA-approved therapies; that leaves 95 percent of patients with no available treatment. Thirty million Americans have rare diseases, including 300,000 in Connecticut.

"There's still a lot of work to be done," he said. "NORD is the voice for the rare disease patient."

He noted that Rare Disease Day is the one day people come together globally to close the gap between the number of rare diseases and the number of available treatments.

NORD has more than 260 member organizations, including Sofia Sees Hope, which unite to promote patient and caregiver advocacy, and research for treatment and cures for those with rare diseases.



Hunter Pageau with mom, Sharon, at RDD at the Legislative Office Building in Hartford

Also in attendance was Hunter Pageau, an articulate North Haven, CT, seventh-grader who is one of 80 people in the world with Spinal Muscular Atrophy with Respiratory Distress (SMARD).

Hunter said he founded a new group called Youth Empowerment Society or YES, and he told the gathering, "While a disease may be rare, hope never should be."

For more information on advocacy and making connections, visit our website at www.sofiaseeshope.org.

LCA Connections

Eye Love Logan 5K and Silent Auction in Colorado

Allison and Michael Galloway's son Logan was diagnosed with Leber congenital amaurosis (RDH12) four years ago. Eighteen months later, their younger daughter was also diagnosed. In addition to being advocates for the health of their children, they became involved in advocating for others in the LCA community.

As part of their fundraising for research advancement, while also raising awareness for LCA, they host a 5K road race in their hometown of Westminster, CO. 2018 will mark the third annual Eye Love Logan 5K and Silent Auction. This is a family-friendly event with a kid fun-run, free balloon animals, face painting, and live music. Walkers, joggers and serious runners are encouraged to participate. The race is August 26; register here **runsignup.com/Race/CO/Westminster/RDH125k**

For those who can't do the 3.1-mile run, there is a silent auction during and after the race with some amazing packages, including vacations, sports tickets and so many local items. 100 percent of the proceeds go to funding the RDH12.org foundation.

For those who can't make it the day of the event, there is online donating that goes live in the spring.

The first year of the event the Galloways raised $35,000 and the second year about $41,000.

Do you hold an event, fundraiser or awareness raiser for LCA? Share it with us! Email elissa@sofiaseeshope.org.

The *Seeing Hope* newsletter is published quarterly by Sofia Sees Hope, a 501(c)3 patient advocacy organization dedicated to generating awareness, raising funds for research, and providing education and outreach to the LCA and rare inherited retinal disease community.

To learn more about Sofia Sees Hope visit our website at www.sofiaseeshope.org.

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