

From the Director



In early 2026, our community has reason for hope. This year marks a milestone for individuals and families affected by Leber congenital

amaurosis (LCA), as three Phase 3 clinical trials—LCA5, CEP290, and GUCY2D—are now underway.

These Phase 3 trials reflect years of scientific dedication, advocacy, and partnership. They are a testament to the courage of participating families, the commitment of researchers and industry, and the support of donors. Thank you to everyone whose engagement and generosity continue to drive progress.

At Hope in Focus, we are committed to keeping families informed, supported, and empowered throughout these trials. We will provide clear updates, promote research literacy, and stand with you as decisions arise.

While there is still work ahead, 2026 begins with real momentum, and that momentum belongs to our community.

With deep gratitude,

Courtney Coates,
Executive Director

Through Unseen Challenges: Finding a Diagnosis

By Katherine L. Kraines, MS

Amanda Geffre gripped the steering wheel of her car as she fought back tears. The two-hour trip home from Fargo, ND, with her two-year-old daughter, Pepper, felt far longer than the trip from their home in Oakes earlier that day. Pepper's appointment with the Fargo pediatric ophthalmologist was supposed to be for updated glasses or maybe bifocals. Amanda hadn't expected new information, and her mind now churned with the implications of the doctor's observations.

She called her husband, Jordan, struggling to find the words to explain what the doctor had said: Pepper had permanent vision loss and damage to her retinas. "I was confused and in shock. The doctor mentioned grieving, but I couldn't grasp what he meant," Amanda recalled.

For several years, the Geffres had been trying to uncover what was impeding their daughter's development. "When we discovered that she had some vision loss, we hoped that glasses and the state's early intervention program would meet her needs," Amanda said. "We never expected a diagnosis of a rare genetic condition."

Early Questions and Uncertainty

Connor, the Geffres' first child, was born in 2014 and met all his milestones. But when Penelope ("Pepper") arrived in 2017, Amanda and Jordan quickly noticed she lagged behind. "When she was about six months old, our pediatrician told us she should be evaluated," Amanda said. "At 11 months, she wasn't crawling, and she qualified for early intervention. But we still didn't know the cause."



The Geffre Family
Maverick, Jordan, Amanda,
Pepper, Jade, and Connor

Through Unseen Challenges: Finding a Diagnosis

Continued from page 1

Pepper disliked getting dressed and had separation issues when she couldn't hear Amanda's voice. "She also avoided physical activities or touching things," said Amanda. "We wondered if she had hearing, or balance problems, or maybe a sensory disorder."

Pepper's inconsistent behaviors made it difficult to pinpoint a cause. For example, when she started eating finger food, sometimes she'd grab it right away, at other times, Amanda would have to tap on the tray or point it out before she'd find it. If she dropped a toy, she might have a hard time locating it, but not always.



Pepper Geffre

When Amanda mentioned these behaviors to the early intervention team, they suggested she might need glasses. An appointment with a local eye doctor, when she was about 18 months old, confirmed that need. "Once she had glasses, Pepper started walking, and we thought the problem was solved," Amanda recalled. "But she continued to trip or walk into things. It seemed like the glasses weren't working, and we felt that something wasn't right." It was then that their local eye doctor suggested a stronger

prescription or bifocals and referred Pepper to the pediatric ophthalmologist in Fargo.

On the Road...Again

Much to Amanda's surprise, the pediatric ophthalmologist said a new prescription was the least of his worries. "He said Pepper had vision loss and that her retinas weren't healthy," Amanda explained. "He also wanted to schedule a brain MRI to see if something brain-related might be causing her vision loss." Although it felt somewhat contradictory, the couple hoped the MRI might reveal something that could restore Pepper's vision. But the test was clear, and the conclusion was that their daughter's vision loss was genetic.

The next referral was to a specialist in the Twin Cities (Minneapolis/Saint Paul, MN). That specialist wasn't concerned, saying that Pepper had moderate vision loss. But he wanted to evaluate her retinal function with an electroretinogram (ERG). Unfortunately, the test was delayed by the COVID shutdown.

"Pepper had the ERG somewhere between ages two and three," said Amanda. "Afterwards, the doctor said he was worried about her vision and that we should connect with the North Dakota School for the Blind. He told us genetic testing was expensive and he didn't think it was necessary."

Genetic Testing

Fortunately, their local eye doctor was able to arrange for free genetic testing, and Pepper was subsequently diagnosed with the recessive *IQCB1/NPHP5* mutation that causes Leber congenital amaurosis. In addition to vision loss, this mutation can cause end-stage kidney failure. "Getting Pepper's LCA diagnosis

consumed me," Amanda said. "It was all I could think or talk about. I Googled everything. No one could tell us what her vision might eventually be like."

Amanda and Jordan underwent genetic testing to determine if they were carriers or whether Pepper's LCA was due to a spontaneous mutation. "When we found that we were carriers, I was in my second or third trimester with our son, Jade," Amanda said. "We now knew that he had a 25 percent chance of having LCA." Jade, tested soon after his birth in 2021, did not have LCA.

Pepper's Progress

The support from the state's early intervention program and vision services was key to Pepper's development. "I was so relieved when she started walking and using a kind of rolling plastic rectangle that they provided," said Amanda. "She could move and run because she understood that this thing she was pushing would detect if there was something in the way. It really helped her developmentally."

Then, just before Pepper turned three, their school district opened a special education preschool. Amanda said it was a battle for Pepper to qualify because the division teacher didn't understand her diagnosis or the extent of her vision loss. Once that problem was rectified, she qualified and began learning braille and how to read and write.

As time went on, the Geffres grew comfortable with Pepper's development. She began using a cane and was telling her parents what was and wasn't working. "She was doing so well in school, we kind of forgot that we had a risk of LCA if we had another child."

Baby #4...

Pregnant with their fourth child, Maverick, the Geffres faced the possibility that this baby could have LCA. "I told myself if it happened again, we knew what to do, who to contact, and who would need to work with this child," Amanda said.

Maverick was born in 2024 and was diagnosed with LCA. "Even though we were somewhat prepared, it was still very hard," recalled Amanda. She called the early intervention team and vision services, and Maverick qualified right away.

Although Maverick's vision was better than Pepper's, he still had developmental delays. "I was a little disappointed since I hoped that by starting him early, he wouldn't be as delayed. He was still not walking at 17 months, even though he had gotten glasses at four months old," Amanda said. "But his physical therapist said that a child with visual impairments is going to be delayed and will have a different developmental timeline."



Maverick Geffre

When Maverick was about six months old, the Geffres took him to the same pediatric ophthalmologist in Fargo who had seen Pepper. But their visit was confusing. "He didn't think the genetic test was correct and said that Maverick's retinas looked fine, and that maybe he had retinitis pigmentosa. That made us wonder

if his genetic testing could have been messed up," Amanda said.

Finding Clarity

A turning point occurred when the Geffres met another family in North Dakota with a son who had LCA, and their recommendation provided Amanda and Jordan with a vital resource. "They were seeing a specialist in retinal diseases in Philadelphia, and encouraged us to see him," Amanda said. "I wasn't sure if he would see Maverick because he was so young, but we really needed someone to tell us what was going on! So, we reached out to the specialist in Philadelphia, and he said he would see an infant."

Both children were evaluated by Tomas Aleman, MD, of the Scheie Eye Institute, which is part of Penn Medicine at the University of Pennsylvania. "He said that Pepper and Maverick had the most vision of children with LCA that he has seen to date. That was somewhat comforting, knowing that at this point they are on the low end of the spectrum and are pretty fortunate," Amanda said.

The Geffres know that both children will have more vision loss, but for now, they take comfort in knowing that their children's diagnosis is accurate. Dr. Aleman explained that vision loss with *IQCB1/NPHP5* is generally a slow progression with loss and then a period of stability. Because *IQCB1/NPHP5* can also cause kidney failure, both children are being regularly monitored via bloodwork and ultrasound.

Life in Motion

The entire family, including Amanda's parents, attended the Hope in Focus Family Conference this past June. "It was so good! My kids really enjoyed it, and we met another family with a daughter who has LCA and lives in Iowa. She is two or three years older than Pepper, but they made a connection and have been talking," Amanda said. "It's been

great for Pepper because she feels like she has an older friend, and they have the shared experience of LCA."



Pepper, Jade, Connor, and Maverick

Despite the Geffres' initial frustrations, the family is forging ahead. Bright-colored tape marks the stairs and other obstacles in their home. It is an ongoing challenge to keep the furniture in the same place—their energetic children, Connor (age 11), Pepper (age 8), Jade (age 4), and Maverick (age 1), love rearranging it. Everyone is adjusting and adapting to the unexpected challenges and joys that arise in a family living with LCA. "We don't know exactly what the future holds, but we're facing it together," said Amanda.

If you, or someone you know, has an inherited retinal disease due to mutations in the *IQCB1/NPHP5* gene, email info@hopeinfocus.org to join our contact database so we can give you up-to-date happenings with your gene.

LIGHT AT THE END OF THE TUNNEL: LCA6 Gene Therapy Advances Toward Clinical Trial



Ben Shaberman,
Science Communications Advisor
Hope in Focus

I am excited to report on impressive progress in the development of Odylia Therapeutics' emerging gene therapy for retinal degeneration caused by *RPGRIP1* mutations, which is most often diagnosed as LCA6. Like the journey for so many inherited retinal disease treatments and the companies that develop them, there's a long story here—a story of commitment, resourcefulness, and persistence. I'll touch on that in a moment, but I encourage you to learn much more from an enlightening Hope in Focus podcast interview I conducted with Ashley Winslow, PhD, chief executive officer at Odylia, on March 3. It's an excellent episode, if I do say so myself.

Background on *RPGRIP1*-associated disease

The *RPGRIP1* protein is critical for the structural development of photoreceptors (rods and cones) and the trafficking of important proteins. Remember, photoreceptor cells are long, thin, light-sensing cells in the retina that enable us to see, and many different proteins need to move up the length of the cells for them to work properly and survive long term. That movement is called trafficking.

Also, remember that genes are like recipes for proteins. Cells read genetic messages to make proteins, and ultimately, it's the proteins that are critical to our cells' function and survival. In the LCA6 case, if there are spelling mistakes (i.e., mutations) in the *RPGRIP1* gene, there isn't sufficient *RPGRIP1* protein produced, and photoreceptors suffer.

Mutations in the *RPGRIP1* gene cause LCA6 but can also be associated with milder forms of retinal disease, such as cone-rod dystrophy (CORD), retinitis pigmentosa, or achromatopsia. Though LCA6 usually causes significant vision impairment at birth, photoreceptors can potentially survive into young adulthood, thereby providing a wide treatment window for patients.

The *RPGRIP1* gene therapy story

Initial development of Odylia's gene therapy began at Mass Eye and Ear (Harvard) more than 15 years ago. Researchers there demonstrated efficacy for

gene therapy in mouse models. With sustained funding from Odylia, the *RPGRIP1* gene therapy has moved into a safety and toxicology study, a critical step before moving into a clinical trial. The study will also help researchers determine the optimal dosing range for the trial. Also important, Odylia has clinical manufacturing in place and received positive feedback from the FDA on the trial design. However, additional funding is needed to launch the trial.

Odylia also has gene therapy programs underway for vision loss due to mutations in the *USH1C* and *NPHP1* genes, which are in preclinical development.

The Odylia story

Odylia was formed in 2017 as a nonprofit collaboration between Scott Dorfman, a father of two children with Usher syndrome 1C, and gene-therapy pioneer Luk Vandenberghe, PhD, of Mass Eye and Ear. Their goal: Provide the commitment and resources needed to advance rare disease treatments into early-stage clinical trials. In the podcast, Dr. Winslow said that as a nonprofit, Odylia has a stronger commitment to rare disease therapy development than a typical for-profit biotech or pharmaceutical company that's focused on minimizing financial risk and maximizing revenue. By de-risking therapies through early-stage development, Odylia aims to attract investment partners (i.e., for-profits) to its programs.

Dr. Winslow explained that the key to Odylia's success is its collaboration with patient groups, academic researchers, manufacturers, and clinical research organizations to find a way forward both in fundraising and therapy development. "In the rare disease space, you have to think about the science and the fundraising hand in hand because financial resources are often limited," she said.

If you're interested in learning more about Odylia and its emerging therapies, you can reach out to Dr. Winslow at awinslow@odylia.org.

And make sure you check out the [Odylia episode on the Hope in Focus podcast](#) (Episode #8 with Dr. Ashley Winslow dated March 3, 2026).



LCA Clinical Development Pipeline Chart

Type-Gene	Modality	Sponsor	Stage	Comments
LCA1 (<i>GUCY2D</i>)	AAV gene therapy (<i>GUCY2D</i>)	Atsena Therapeutics	Planning Phase 3	Vision improvements in Phase 1/2
LCA2 (<i>RPE65</i>)	AAV gene therapy (<i>RPE65</i>)	Genentech	LUXTURNA®: Approved by FDA, EMA	Hundreds dosed after approval, most with vision improvements
LCA2 (<i>RPE65</i>)	AAV gene therapy (<i>RPE65</i>)	HuidaGene Therapeutics	Phase 1/2	Vision improvements reported
LCA4 (<i>AIPL1</i>)	AAV gene therapy (<i>AIPL1</i>)	MeiraGTX Eli Lilly	MHRA Specials License	Vision improvements for 11 young children
LCA5	AAV gene therapy (<i>LCA5</i>)	Opus Genetics	Recruiting Phase 3	Vision improvements in Phase 1/2
LCA10 (<i>CEP290</i>) (IVS26 mutation)	RNA therapy targeting IVS26 mutation in <i>CEP290</i>	Sepul Bio	Recruiting Phase 3	Vision improvements in the previous Phase 1/2 and 2/3

Don't see your gene listed? Visit www.hopeinfocus.org for additional information on therapies in preclinical development.

NOW ENROLLING

Approved by Sterling IRB, IRB ID: 13589

A Clinical Trial for LCA5-associated Inherited Retinal Disease (LCA5-IRD)

Opus Genetics is sponsoring a clinical research trial evaluating an **investigational gene therapy for participants 4 years of age and older affected by LCA5-associated IRD**

There is no cost to participate and travel support is available.

To learn more about the clinical study, contact:

> **University of Pennsylvania Perelman School of Medicine | Philadelphia, PA**

Mariejel Weber, Clinical Coordinator
mariejel.weber@pennmedicine.upenn.edu
+1 (215) 662-6396

> **Retina Foundation of the Southwest | Dallas, TX**

Martin Klein, Research Coordinator
mklein@retinafoundation.org
+1 (214) 363-3911

CLICK HERE for more study details or visit:
<https://clinicaltrials.gov/study/NCT05616793>

©2026 Opus Genetics, Inc.

Envisioning a new future for patients
with inherited retinal diseases



ATSENA THERAPEUTICS is focused on bringing the life-changing power of genetic medicine to reverse or prevent blindness. We have a gene therapy program for LCA1 caused by mutations in the *GUCY2D* gene.

LEARN MORE AT
WWW.ATSENATX.COM

BRINGING
PATIENTS INTO
FOCUS WITH
OCULAR GENE
THERAPY

FOSTERING MEANINGFUL CONNECTIONS

We hosted the **2025 LCA Family Conference** (June 20–21, 2025 in Minneapolis, MN), bringing together families, researchers, clinicians, and industry partners to share the latest updates in treatment development and foster meaningful connections across the LCA community.



2025 LCA Family Conference attendees • Photo taken by Eighty Six Media

ADVOCATING FOR RESEARCH

Hope in Focus continued advocating for **patient-centered research design** and meaningful clinical trial endpoints.



Participants from Atsena Therapeutics Patient Advisory Group during our 2025 LCA Family Conference



EMPOWERING THE COMMUNITY

Hope in Focus introduced our first summer-long fundraiser, **Party for Sight**, empowering community members to raise awareness and funds, like the Bonilla Family did for Eva's birthday party.

CELEBRATING CONNECTION AND IMPACT

Together, we celebrated the 10th annual **Dinner in the Dark** fundraiser (November 1, 2025 at Foxwoods Resort Casino in Mashantucket, CT) marking a milestone year for the event and the community it supports. With your help, we raised over **\$190,000** to advance research, education, and support for those living with rare retinal diseases.



Photo by PubliCreatives

HOPE in FOCUS 2025 HIGHLIGHTS

FAMILY STORIES

We continued to share **family stories from the LCA community**, highlighting real experiences, connection, and hope.



STRENGTHENING LEADERSHIP

We named **Courtney Coates** as **Executive Director**, strengthening Hope in Focus' leadership and positioning the organization for continued growth and expanded programs—like speaking at the Annual Meeting for the American Society of Gene + Cell Therapy (ASGCT) to **connect with a global community** dedicated to **advancing genetic and cellular therapies**.



Jill Chertow (L), Propionic Acidemia Foundation, Courtney Coates, Hope in Focus, Sarah Cortell Vandersypen, Cure MSD and Sharon King (formerly at Andelyn Biosciences) attending ASGCT Annual Meeting in 2025

EXPANDING THE CONVERSATION

We launched the **Hope in Focus Podcast**, expanding access to conversations with researchers, clinicians, advocates, and families affected by inherited retinal diseases, and creating a new platform for education and storytelling.



BRIDGING THE GAP: *Helping others see what you experience*



Jack and his guide dog, Baloo

Over the years, I've learned that many people don't understand that visual impairment is a spectrum. Most people think there are three options: 20/20 vision, vision that can be corrected by glasses, or total blindness.

As a child, I passed as fully sighted in most situations. When I told people that I was visually impaired, their first question often was, "Why don't you wear glasses?" After getting a guide dog, I get fewer questions like that; however, people now assume that I am totally blind.

When people know what you can see, you are more likely to experience environments where you feel included. This is why it is so helpful to be able to explain what you can and can't see in simple terms.

It's also important to take the initiative to share this information.

I describe my vision as looking backward through binoculars while wearing several pairs of sunglasses. This lets people know that things look much smaller to me, that I can't read printed text, and that I can't see in dark/dim lighting. It is much more effective to use this analogy than to list things I can't see.

Sharing my analogy also helps someone to imagine what it would be like to look through binoculars backwards, wearing several pairs of sunglasses. But they often can't imagine what it is like not to see in dim lighting. It is also hard for some people to ask what I can and cannot see since they don't want to highlight my limited vision or are just uncomfortable asking.

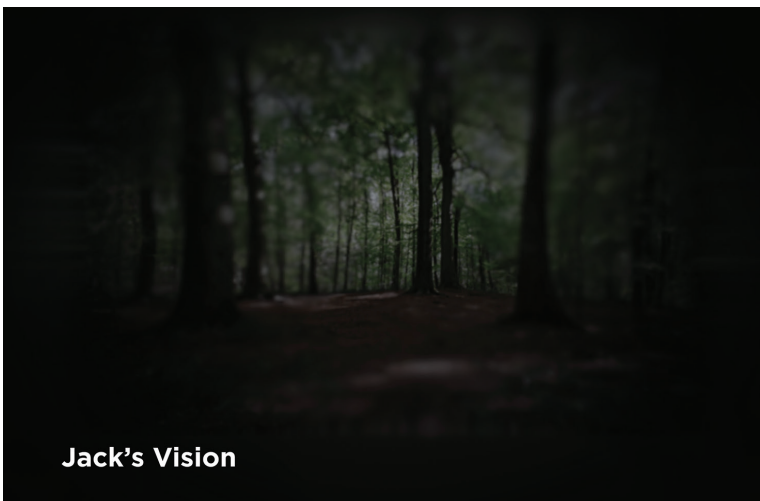
Providing information about your visual impairment or offering an analogy often puts people at ease. When people know you are comfortable talking about it, they feel freer to ask questions.

Imagine playing cards with a new group of friends. One person at the table asks, "Will you be able to play cards with us?" You know you won't be able to see the cards in the center of the table, but you share your vision impairment analogy or description. By helping your friends understand that you can see the cards in your hand but will need them to announce the card that they lay down, allows them to make simple accommodations so you can participate. Because you were able to describe your vision loss simply, you and your friends have a great evening together.

I encourage you to come up with your own analogy to describe how you see. I know I am not alone in worrying about the accessibility of new environments. Most people are happy to do what they can to make things more accessible. Helping them understand what you can see will help them help you and lead to a more fulfilling, connected life.



20/20 Vision



Jack's Vision



Jack McCormick is a human resources professional working in the tech sector. He was diagnosed in high school with LCA2 (RPE65). Jack is a Hope in Focus ambassador, helping people living with LCA and IRDs. Learn more about him on his [LinkedIn profile](#) by scanning the QR code.

We take great care to use every dollar we raise to advance our mission.

In 2025, Hope in Focus hosted our fourth LCA Family Conference. This significant educational event was attended by over 130 community members, researchers, industry leaders, and advocates. A notable portion of our budget was allocated to support this important initiative, as it aligns closely with our mission.

To better serve our community, we expanded our team to include two full-time staff members and engaged new part-time contractors to enhance community engagement, communications, and development. These essential investments enabled us to launch new educational programs, including the Hope in Focus podcast in 2025.

Dinner in the Dark remains a flagship event for our organization, generating half of our annual revenue. However, we took deliberate steps during the past year to diversify our income sources by exploring new partnerships with industry leaders in drug development, also allowing us to incorporate our community's voice into upcoming clinical trials.

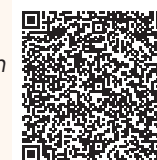
Looking ahead...

Hope in Focus operates in a dynamic landscape that is constantly evolving. As treatment research advances into later-stage clinical trials, our global community continues to grow, thanks to improved access to genetic testing and enhanced connectivity to reliable health information. The needs of individuals and families are changing—from understanding a diagnosis to thoughtfully evaluating treatment options, participating in clinical trials, and making long-term care decisions.

To address these needs, we are strengthening and expanding the Hope in Focus team, while also strategically diversifying our funding sources and broadening our base of philanthropic and corporate support. Sustainable growth is essential to ensure that we can continue to provide trusted education, meaningful connections, and a strong patient voice in research and regulatory discussions.

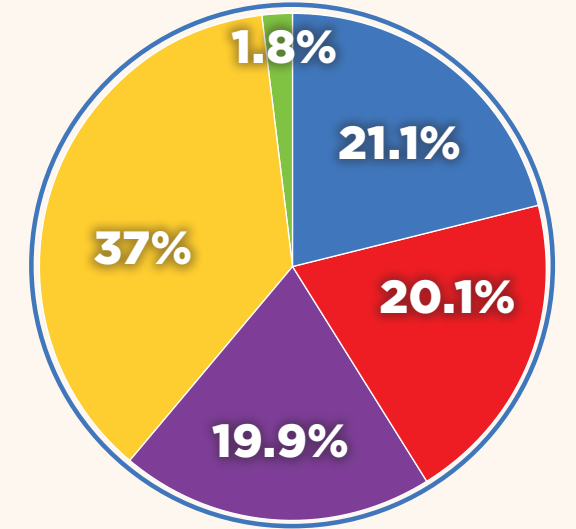
We invite you to join us in this next chapter. Your support allows Hope in Focus to accelerate research progress, empower families with knowledge, and ensure that the lived experiences of our community remain at the forefront of every advancement.

For more detailed information and to view our past Form 990s, [visit our profile on Candid](#) (formerly GuideStar).



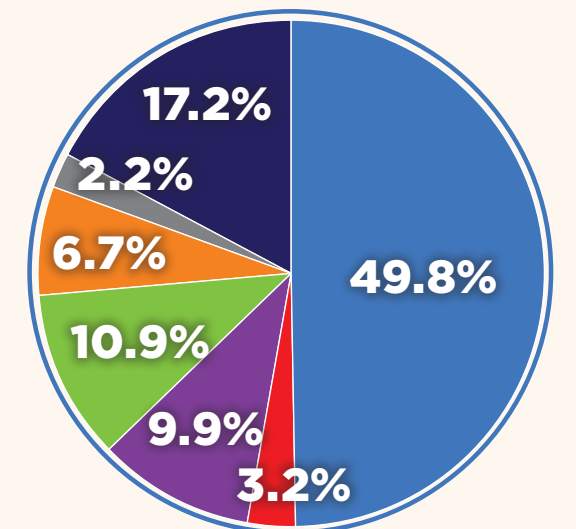
2025

EXPENSES



- Fundraising Events
- General & Administration
- Programs (LCA Conference)
- Programs (Outreach & Education)
- Industry Services

INCOME



- Dinner in the Dark
- Other Fundraising Events
- Programs (LCA Conference)
- Industry Services
- Corporate Giving
- Grants
- Direct Support

Thank You

FOR YOUR SUPPORT IN 2025!

INDIVIDUALS

Jessica & Edward Allen	Michelle Claffey	Sheryl & Craig Floyd
Melissa & Michael Allen	Susan & Wayne Clark	Carol Foley-Ambrosch
Danya Alper	Robert Comerford	Sarah Weber Gallo
Cristian Alvis	Amy Concannon	Lisa Gardiner
Jackie & Nate Andersen	Christian Coronado	Alexa & Michael Garvey
Devin Andersen	Blair & John Corso	Conner Gavin
Lori & Lee St. Arnaud	Georgia Corso	Jack Geffken
Leah Arnold	Sariye & Chris Cote	Jeanne Gilbert
Rachel Arnold	Rachel Crabtree	Brandon Graber
Anabel Averso	Mary & Bruce Crawford	Elizabeth Graczyk
Brenda & Eric Balch	Guy Crepeau	Ellin Grenger
Cari & William Barnes	Hal Crimm	Matthew Griesinger
Tina Batoh-Jennings	Josephine & David Cruthers	Bonnie Hansen
Mallory Bissett	Jodie Danko	Atsushi Hashimoto
Augusto Bonilla	Rosanne & Nicolo DeBari	Heather & Andrew Hatch
Robert Boris	Mary L. DiGiacomo-Cohen & David Cohen	Lorraine Healy
Paul Bourguignon	Amy & Kenneth DiRico	Betty & Ron Helbig
Margaret Bowersox	Lisa Dogolo	Margaret Hirsch
Leslie Brennan	Martha Dow	Laura & Adam Hoffacker
Marcie & Howard Brensilver	Kristen D'Souza	Jerrilyn Holst
DJ & Brendan Broadbin	Tony Duong	Frances Hopper
Theresa Broadbin	Kristin Eidam	Linda & Edward Hutter
Stephanie & Kyle Brown	Suzanne Ellery	Jill Iacono
Mark Bundesmann	Marjory Elwell	Alexis & Benjamin Kahn
Lisa & Bob Butler	Melissa Mills Endejann	Marc Kallinen
Alexandria Byrd	Maria & Scott Engel	Kyle Keefe
Michael Calandra	Jean Erickson	Cathy & Carl Kellers
Karen & Sal Calandra	Maricarmen Esquivel	Ferdinand Kelley
Sarah & Jason Callahan	Kacko Family	Elizabeth Kelly
Sandra Campbell	Patricia & Edward Favolise	Tim Kenyon
Kim Cardinal	Niki & Henry Fayne	Yuliya Kochiy
Stephane Caron	Jackie Fedor	Brian Kostantin
Margie & Mark Case	Kara Fick	Nancy Ku & Thomas Wei
David Cassenti	Jeffrey Finman & Iva Boas	Manu Kurian
Terry Chiaradio	Debbi Florence	Renee LaBonte

Matthew Laflamme	Diane Neumeier	Margaret & Tony Sheridan
Mary & John LaMattina	Abigail Novak	Franco & Luigi Simeoni
Linda Lange	Jennifer O'Brien	Lisa Sinclair
Rhandi Lee	Renee & Michael O'Farrell	Lucas Slomski
Andrew Lemire & Lauren Andrade	Daniel Orcutt	Betty & Bill Smith
Pat Liebl	Richard Orcutt	Caitlin & Greg Smith
Jessica Loupos	Rose & Tom Orcutt	Julia Smith
Ashley Luppold	Catherine Osten	Kevin W. Smith
Denise Luppold	Cynthia Palmer	Lindsay Smith
Leslie Magnus	Adrienne & Andrew Parad	Sandra Smith
Alessandra Manfre	Allie Parillo	Gayle & Stephen Smith
Betty & Christian Manfre	Katie Parks	Joseph Somers
Cristina Manfre	Kristen Patton	Ann Stimm
Laura Manfre & Charles Priebe	Elaine & Dean Peluso	Anne Stokely
Mary & Robert Manfre	Beth Pite & Paul McCary	Dennis Stokley
Jennifer & Jeff Marshall	Dana & Michael Planeta	Steven Sweeney & Jennifer Dahlgren
Elizabeth & Steven Mauro	Susan & Mark Pochal	Joshua Terry
Laura McBride	Dante Priebe	Ketti & Michael Terry
Jennifer McCracken	Meredith Priebe	Annette Tonti & Steven Turilli
Mark McDonough	Ruthmary & Ed Priebe	Alex Van Rees
Sharon McHugh	Precious Putnam	Madeleine Wedvik
Carrie Melvin	Matt Reese	Libbie & Matt Weinheimer
Kayla & Derek Mills	Trina Reynolds	Gerald Williams
Adam Milne	Beth Ribe	Martha & David Williams
Joan Misa	Susan & Robert Rieger	Amelia Willson
James Mitchell	Andrea & Mark Robinson	Lisa Winkler
Margaret Moffitt	Amanda Rocha	Sandra Worth
Beth & Michael Mondello	Elisse Rosen	Hatice Yayla
Tami & Mike Morehouse	Ana & Jeff Schneider	Amir Yazdanyar
Jennifer & Marc Murray	Karen Stone & David Schulz	Tracy Young
Eduardo Narvaez Boersner	Donna & Daniel Senft	Kellan Ysewyn
Kate Nazemi	Therese Senft	Joann Zamparo
Sarah Nelson	Ann Serpa	Tracy Zimmerman
	Nancy Shepard	

CORPORATE & ORGANIZATIONAL DONORS

Atsena Therapeutics	MeiraGTx
Danielle Marie Senick Memorial Fund	Mystic Lions
Denise D'Ascenzo Foundation	Niantic Lions
Dominion Energy Charitable Foundation	Noesis Capital Management
Entact, LLC	Pfizer Matching Gifts
Hewlett Packard Enterprise Matching Gifts	Simply Majestic
Lions Club of Tolland	Town Fair Tire Foundation

Event Calendar

Do you have an event you want to share? Let us know!
Email info@hopeinfocus.org with the information and a link.

VISIONS 2026: United in Vision

June 12-13, 2026 • Forth Worth Convention Center, Fort Worth, TX

www.fightingblindness.org/visions-2026

The United in Vision 2026 conference unites two prestigious events—the Foundation Fighting Blindness VISIONS conference and the Retina International World Congress—into one extraordinary global gathering. This premier event brings together individuals and families impacted by blinding retinal conditions, alongside leading researchers, clinicians, patient advocates, and industry partners, to foster collaboration, innovation, and hope. Come see us at our booth!



RDH12 Family Conference 2026

June 20, 2026 • London, England

eyesonthefuture.org.uk

Organized by Eyes on the Future and the RDH12 Global Alliance, in partnership with NIHR Moorfields Biomedical Research Centre (BRC), the day will highlight the latest research, emerging developments, and what the future may hold. After years of online meetings, this is a special opportunity to reconnect our global community and share new stories, new science, and new possibilities.



Dinner in the Dark

October 24, 2026 • Foxwoods Resort Casino, Mashantucket, CT

hopeinfocus.org/events/dinner-in-the-dark

Dinner in the Dark, our primary fundraiser for the year, helps fund research to cure blindness caused by LCA, provides support for genetic testing, and drives awareness, education, and connections for LCA and IRD families. Get ready for an incredible evening that is a lively sensory adventure with a stellar menu, fine wines, and more!



A New Look for Our Website

We're excited to share a refreshed look for hopeinfocus.org. You'll find resources on genetic testing, research and clinical updates, community stories, events, and ways to get involved. It's a valuable resource—whether you're looking for information, connection, or ways to support our work.



We're especially grateful to the team at [Drink Caffeine](http://DrinkCaffeine.com) in Madison, Connecticut, who generously donated their time and talent to make this update possible. We hope you'll take a look and stay connected as we continue working toward our mission. Scan the QR code or visit hopeinfocus.org to check it out!



P.O. Box 705 | Ledyard, CT 06339

The **Seeing Hope Newsletter** is published quarterly by Hope in Focus, 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 Hope in Focus, visit www.hopeinfocus.org.

Seeing Hope Newsletter Team

- Courtney Coates, Executive Director
- Katherine L. Kraines, MS, Communications Manager
- Genevieve (Eve) Orcutt, Marketing and Community Engagement Manager
- Ben Shaberman, Science Communications Advisor
- Gina Morin, Graphic Designer

This newsletter is made possible by the generosity of:

- Atsena Therapeutics
- Genentech
- Opus Genetics