

## Foundation Fighting Blindness Commits More Than \$15 Million to 23 Promising Research Projects for Eradicating Retinal Diseases

*Funding for the new grants was made possible by Foundation's strong donor base and philanthropic partners.*

The Foundation Fighting Blindness added 23 new research projects to its portfolio, an investment totaling more than \$15 million, during its Fiscal Year 2022 (ending June 30, 2022).

Project awards ranged from early-stage lab research to identify treatment targets to translational efforts for advancing emerging therapies toward clinical trials.

Examples of FY2022 grants awarded through our Translational Research Acceleration Program include:

- A \$899,820 grant to Rui Chen, PhD, at Baylor Medical College, who is developing a novel approach for empowering the degenerating mammalian retina to self-regenerate – i.e., sprout its own new photoreceptors. This would serve as an alternative to cell transplantation therapy by reprogramming endogenous cells in the mammalian retina to induce photoreceptor regeneration.
- A \$1,446,827 grant to Maureen McCall, PhD, University of Louisville and the company BioJiva to evaluate a novel mutation-independent oral drug candidate, deuterated DHA, for preserving retinal cones and cone function despite rod death in retinitis pigmentosa.

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## HELP FIGHT BLINDING DISEASES

Use the enclosed envelope to make a life-changing gift.

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## **COVER STORY** **CONTINUED FROM FRONT COVER**

The Foundation also awarded several grants for development of new models for USH1B (MY07A), USH2A, CRB1, PRPF31, EYS, and ABCA4 (Stargardt disease) to better understand disease mechanisms and test potential therapies.

Research grants were selected after a rigorous review process conducted by the Foundation's Scientific Advisory Board, which is comprised of more than 60 of the world's leading retinal scientists and clinicians.

The Foundation's current research portfolio funds a total of 84 projects.

"There is something for everyone with these new investments. The new grants include gene-targeted and gene-agnostic approaches to address the entire spectrum of retinal degenerations that affect people of all ages and backgrounds around the world," said Claire Gelfman, PhD, chief scientific officer at the Foundation. "We greatly appreciate the generosity and commitment of our passionate donor base and funding partners, including the Diana Davis Spencer Foundation, the Free Family Foundation, and Save Sight Now. Ultimately, it's patients, families, and philanthropic groups that drive this outstanding research."

For descriptions of all 23 grants, visit:

**[www.FightingBlindness.org/funded-grants-2022](http://www.FightingBlindness.org/funded-grants-2022)**

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Or visit us at **[www.FightingBlindness.org](http://www.FightingBlindness.org)**.

Physicians differ in their approach to incorporating research results into their clinical practices. You should always consult with and be guided by your physician's advice when considering treatment based on research results.

## VISIONS 2022

# VISIONS 2022: Thank You!

VISIONS 2022— on June 17–18 at Disney’s Coronado Springs Resort— brought together over 400 individuals from the blind and visually impaired community from across the country. Thank you so much to everyone who attended this year, and our speakers and exhibitors for participating! And thank you to our VISIONS 2022 sponsors, including Platinum Partner, Janssen Global Services, LLC, one of the Janssen Pharmaceutical Companies of Johnson & Johnson; Gold Partners, Genentech, and Spark Therapeutics; Silver Partners, AGTC, and Iveric Bio; and Bronze Partners, Apellis, Nacuity, REGENXBIO, and Two Blind Brothers.



**Clockwise, Starting Top Left:** Chad E. Foster on stage speaking during his keynote luncheon session. • Patriot Vision Industries LLC exhibitor booth showing an attendee how to use assistive technology that she’s wearing over her eyes. • Technology session panel (Ed Summers, San Seavey, and Jeff Wissel) on stage. • Paralympian swimmer Becca Meyers speaking in front of attendees.

**Center:** Board Director Karen Petrou receiving the Beverly & Bernard Berman Builders of Sight Award.



## A New Vision Through Music

47-year-old singer, songwriter, and producer Mark Erelli lives in the Boston suburb Melrose, Massachusetts, with his wife, Polly, and two sons.

Mark first became interested in music in junior high school and continued through college, where he started writing his own songs and taught himself how to play guitar while majoring in biology. Mark pursued both science and music for a while, but after earning his master's degree in evolutionary biology, he knew he'd always regret not trying to follow his musical dreams. Twenty-three years later, Mark's now a full-time folk musician that plays guitar, mandolin, drums, and harmonica.

One night in the summer of 2020, Mark was performing on stage when he looked down in the middle of a song and couldn't see where his fingers were on the neck of his guitar. A few weeks later, Mark was coming home from visiting a friend, and as he drove through a short tunnel realized that he couldn't see the other end—everything just went black. After both of these unsettling and terrifying experiences, Mark went to his optometrist in September 2020, thinking he probably just needed glasses. His optometrist told Mark he did need glasses, but his retinal imaging was also troubling. After a full day of testing with a retina specialist at Mass Eye and Ear in mid-October of 2020, he was diagnosed with retinitis pigmentosa (RP). Mark also received genetic testing, and during his genetic counseling, he recalls feeling thrilled.

"I was excited to speak with a genetic counselor and learn about my particular mutation," says Mark. "I think she was a little



Mark Erelli sitting and holding his guitar.

shocked because most people don't react so positively, but many gene therapies are being developed, and knowing my exact genetic issue makes it easier to find a solution. I'm hopeful that now I might one day be able to participate in a future treatment."

Being diagnosed with RP during the height of COVID felt isolating for Mark. Without easy access to his usual community of friends and family, it was a unique time to get a life-changing diagnosis. But because he also wasn't working and traveling, with live performances being halted and slowed down from the pandemic, Mark was better able to process and cope with his diagnosis with fewer distractions.

After taking some time for himself, Mark felt there was no sense in hiding his diagnosis from his fans, so he wrote an email newsletter sharing his news. He was shocked by how many people responded with their similar stories and journeys with disabilities.

"Being honest with my audience has opened me up to this wellspring of support and now seems to have given others the courage to open up too," says Mark. "I'm newly diagnosed and still getting used to referring to myself as having a disability. Hearing what other people are struggling with made me feel a lot less alone. You don't really know what others are grappling with day-to-day, so I always have to remind myself to be patient with others if I want them to be patient with me."

One of Mark's best-known songs is "By Degrees," which was written before his diagnosis and begins with the lyrics, "When I take a look around me, sometimes I wish I was blind." Mark says that hits him so differently now, and he suspects his audience feels it too.

Another way Mark found a sense of community and hope was by connecting with the Foundation Fighting Blindness. Mark first found out about the Foundation through the My Retina

Tracker® Registry after his genetic testing. He then learned about the Foundation's livestream music series, *Music to Our Eyes*, featuring Grace Potter, having no idea that she too had vision loss.

"As a songwriter, you need your powers of observation, compassion, and empathy to write songs that connect with people," says Mark. "This whole experience has deepened and strengthened my sense of compassion for others. And now I don't take anything for granted."

Mark has a new album coming out in early 2023 called *Lay Your Darkness Down*, which was written largely right before and following his diagnosis with RP. His 14th solo album, this project is unique since it was all recorded in his home studio. The word "blind" or "blindness" doesn't appear anywhere on the album, but his experience with RP has infused the entire album. A song called "Up Against the Night" was actually written in 2018, but once diagnosed, the song's meaning changed and turned out to be a perfect fit for what he's been going through.

"This album started as a way to distract myself from my diagnosis," says Mark. "But it also was a way to prove to myself that even though I was losing agency in some areas of my life, I still have enough creative agency that I can record and make music on my own."

In October, the Foundation's *Music to Our Eyes* livestream will feature Mark Erelli. To listen to Mark's music, visit his website at: [www.MarkErelli.com](http://www.MarkErelli.com)

## CLINICAL-TRIAL PIPELINE

# Retinal-Disease Therapy

Inherited Retinal Diseases and Dry AMD: 39 Trials (select) | Updated September 2022

GENE THERAPIES (GENE TARGET)	PROGRESS
Achromatopsia (CNGB3) – AGTC	Phase 1/2
Achromatopsia (CNGB3) – MeiraGTx/Janssen	Phase 1/2
Achromatopsia (CNGA3) – Tübingen Hosp	Phase 1/2
AMD-dry – Gyroscope	Phase 2
Batten disease (CLN5) – Neurogene	Phase 1/2
Choroideremia (REP1) – 4DMT	Phase 1/2
Choroideremia (REP1) – Tübingen Hosp	Phase 2
LCA (GUCY2D) – Atsena	Phase 1/2
LCA (CEP290, CRISPR) – Editas	Phase 1/2
LCA and RP (RPE65) – MeiraGTx/Janssen	Phase 1/2
RP (PDE6B) – Coave	Phase 1/2
RP (RLBP1) – Novartis	Phase 1/2
RP (NR2E3, RHO) – Ocugen	Phase 1/2
RP (PDE6A) – Tübingen Hosp	Phase 1/2
Retinoschisis (RS1) – NEI	Phase 1/2
X-linked RP (RPGR) – AGTC	Phase 1/2
X-linked RP (RPGR) – MeiraGTx/Janssen	Phase 1/2
X-linked RP (RPGR) – 4DMT	Phase 1/2

RNA/OTHER THERAPIES (MECHANISM)	PROGRESS
AMD-dry (CB inhibitor) – Ionis	Phase 2
AMD-dry (C5 inhibitor) – Iveric bio	Phase 2
RP, Usher, others (optogenetic) – Bionic Sight	Phase 1/2
RP, Usher, others (optogenetic) – GenSight	Phase 1/2
RP, Usher, others (optogenetic) – Nanoscope	Phase 2

CELL-BASED THERAPIES (CELL TYPE)	PROGRESS
AMD-dry (RPE) – Lineage	Phase 1/2
AMD-dry (RPE) – Luxa	Phase 1/2
AMD-dry (RPE from iPSC) – NEI	Phase 1/2
AMD-dry (RPE on scaffold) – Regen Patch	Phase 1/2
RP, Usher (retinal progenitors) – jCyte	Phase 2b
RP (neural progenitor cells) – Cedars-Sinai	Phase 1/2

SMALL MOLECULES (MECHANISM)	PROGRESS
AMD-dry (C3 inhibitor) – Apellis	Phase 3
RP (NAC-anti-oxidant) – Johns Hopkins	Phase 2
RP (methotrexate) – Aldeyra	Phase 2
RP (small molecule) – Endogena	Phase 1/2
Stargardt disease (emixustat) – Kubota	Phase 3
Stargardt disease (deuterated vit A) – Alkeus	Phase 2
Stargardt disease (C5 inhibitor) – Iveric bio	Phase 2
Stargardt disease (anti-RBP4) – Belite Bio	Phase 3
Stargardt disease (metformin) – NEI	Phase 1/2
Usher syndrome (NACA-anti-oxidant) – Nacuity	Phase 1/2

For more details and trial contact information, visit [www.FightingBlindness.org/Clinical-Trial-Pipeline](http://www.FightingBlindness.org/Clinical-Trial-Pipeline). This document is for informational purposes only. Information is subject to change, and its accuracy cannot be guaranteed.

## Shop the Foundation Merchandise Store

The Foundation Fighting Blindness has an official merchandise store – designed to raise awareness and support the Foundation’s mission! Show off your support of the Foundation with various branded merchandise and apparel, like t-shirts, hoodies, hats, YETI® tumblers, and more.

Check out the website by visiting: [www.ShopFightingBlindness.org](http://www.ShopFightingBlindness.org)

## COMMUNITY SPOTLIGHTS

# Lulie's Light Awards

This year at the VISIONS conference, the Foundation had the pleasure of awarding the first of many Lulie's Light Awards to three deserving Chapters. These awards were created in memory of Lulie Gund who understood the importance of connecting with our communities to share the latest research advancements, and to provide access to local resources to guide individuals through their personal journey. Lulie's Light Award will annually recognize the work and impact of the Chapters network around the nation.

We are honored to award the following Chapters as the inaugural year Lulie's Light Awardees.

- Community Champion Award – Bay Area Chapter
- Pathmaker Award – Los Angeles Chapter
- Guiding Vision Award – Jacksonville, Florida Chapter

These Chapters, as well as all our other Chapter leaders and members, are generous with their time and talents, they bring light and vision to many incredible efforts that impact their local communities. Each Chapter will be hosting in-person Speaker Series and Vision Seminars this Fall to help continue to drive these efforts forward.

To learn more about our Chapters or to find out about our in-person activities being hosted this Fall, reach out to us at:

**Chapters@FightingBlindness.org**



Chapter President Eric Zankman receiving his Community Champion Award for the Bay Area Chapter.



Chapter President Jessie Wolinsky receiving her Pathmaker Award for the Los Angeles Chapter.



Chapter President Adriann Keve receiving her Guiding Vision Award for the Jacksonville Chapter.



## EVENTS SPOTLIGHTS

# Microsoft Scramble for Sight Golf Tournament

The 22nd Annual Microsoft Scramble for Sight Golf Tournament presented by RE/MAX took place on July 18, 2022, at the exclusive Sanctuary Golf Course in Sedalia, Colorado. The event was a total ace, raising over \$330,000 for the Foundation Fighting Blindness, thanks to the amazing donors and sponsors. The golfers had the special opportunity to compete against professional long drive entertainer Andrew Eigner, who also performed an exhibition of long drives and trick shots for the attendees. The dinner program included an interactive and heart-felt generational panel discussion that raised awareness of the meaningful and important work of the Foundation. Thank you to the event co-chairs Scott Burt and Sheri Kroonenberg, and the auction chair Lindsey Blankenship.



Attendees outside on the green at the 22nd Annual Microsoft Scramble for Sight Golf Tournament.

## It is VisionWalk Season!

VisionWalk is taking place in 13 communities across the country this season—with 20 more planned in the spring of 2023. These fun, family-friendly events will bring together hundreds of teams and thousands of walkers as we take steps toward treatments and cures for blinding retinal diseases.

“As a family impacted by blindness, we are ready to help push the mission forward—and the Foundation Fighting Blindness and VisionWalk provide the resources needed to do it,” says Brett Schmidt, Charlotte VisionWalk Chair and captain of Team Henry. “There are so many ways you can be part of this amazing community, and signing up for your local VisionWalk is a great first step.”



Members of Team Brett outside at the Charlotte VisionWalk.

To find the nearest VisionWalk to you, visit [www.VisionWalk.org](http://www.VisionWalk.org) or call (800) 683-5555.



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## RESEARCH HIGHLIGHTS

### **Kiora to Launch Clinical Trial in Australia for Vision-Restoring Small Molecule for RP Patients**

Kiora Pharmaceuticals has received authorization to launch a clinical trial for KIO-301, its emerging small-molecule therapy to restore vision in people with advanced retinitis pigmentosa (RP) and potentially other retinal conditions. Known as the ABACUS study, the Phase 1B clinical trial will take place at The Royal Adelaide Hospital (RAH) in Adelaide, South Australia, and will begin enrolling patients in the third quarter of 2022.

KIO-301 is known as a “photoswitch,” a light-sensitive small molecule designed to bestow light

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### **Endogena Launches Clinical Trial of Therapy to Activate Stem Cells in RP Patients’ Retinas**

Endogena Therapeutics has dosed the first patient in its Phase 1/2 clinical trial for E-2353, its small molecule designed to activate dormant retinal stem cells in the eyes of patients with RP to produce photoreceptors, the retinal cells that make vision possible but degenerate in RP. The endogenous retinal stem cells migrate from the ciliary epithelium, located just behind the iris, to the retina, where they develop into photoreceptors. The treatment is designed to work regardless of the gene causing the RP.

The 14-participant trial will take place at six sites in the US. Participants will receive the treatment through an injection into the vitreous, the soft gel in the middle of the eye. Each patient will have one eye treated.

sensitivity to ganglion cells that are downstream from degenerated rods and cones. KIO-301 will be delivered through monthly intravitreal injections.

The Foundation Fighting Blindness provided \$1.3 million in funding through its Translational Research Acceleration Program and a Gund Harrington Scholar Award to Richard Kramer, PhD, University of California, Berkeley, for the development of related photoswitches for restoring vision.

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### **Luxa Doses First Participant in Clinical Trial of RPE Stem Cells for Dry AMD Patients**

Luxa Biotechnology has announced transplantation of retinal pigment epithelial stem cell-derived RPE (RPESC-RPE-4W) in the first participant in its Phase 1/2 clinical trial for people with dry age-related macular degeneration (dry AMD). Dr. Rajesh Rao, the trial principal investigator at the Kellogg Eye Center, University of Michigan, transplanted 50,000 RPESC-RPE-4W cells under the macula of a legally blind participant with dry AMD. The 18-participant trial starting in Ann Arbor, Michigan, is the first in human study of RPESC-RPE-4W for the treatment of a retinal disease. The trial is evaluating three different cell doses: 50,000, 150,000, and 250,000 cells.

RPE cells provide critical support functions, including nutrition and waste management, for the photoreceptor cells that initiate vision in the retina. In macular conditions such as AMD, the dysfunction and degeneration of RPE cells leads to loss of photoreceptor cells and central vision that can progress to legal blindness.

The company’s RPESC-RPE cell product is composed of progenitor-stage RPE cells grown from human eyes donated to eye banks.

## BEACON STORY

# Passionate Professional Outreach Volunteer Helping Newly Diagnosed

At 37 years old, Jim Shirk was diagnosed with retinitis pigmentosa (RP). The news came as a complete shock to Jim, as he wasn't showing any symptoms and had never even heard of RP before. Jim was participating in a study for his cardiologist, and as part of the study, an ophthalmologist examined his eyes and he was told he had something called RP. The doctor said there was no treatment or cure for this disease and that it commonly leads to complete blindness. That feeling of hopelessness is what drives Jim's passion for helping the Foundation Fighting Blindness' Professional Outreach team now.

Jim's RP developed slowly at first, but in the last 8-10 years, Jim's vision loss has started progressing more rapidly. On his own, Jim eventually received genetic testing and learned that his RP is caused by mutations in his USH2A gene and that it's recessive. Through assistance from the Opportunities for Ohioans with Disabilities, Jim received services from the Cincinnati Association of the Blind & Visually Impaired (CABVI). Jim has learned to use voice-over technology on his iPhone, JAWS software, an HD magnifier, and mobility training with a white cane.

Now 60 years old, Jim lives in Mason, Ohio, a suburb of Cincinnati, and has been married for almost 37 years to his, as he describes, compassionate, patient, and caring wife, Peggy. Jim and Peggy have three sons, none of which are affected by RP. For 30 years, Jim was a manufacturer's representative and eventually one of the owners of a firm called Ketchum & Walton, retiring about five years ago.

"I feel very grateful for the life that I have," says



Jim Shirk in front of a tent with Rosie's Pickles at the Cincinnati/Northern Kentucky VisionWalk.

Jim. "I learned in a support group several years ago that our interactions with people may be the first time they're ever meeting someone that is blind or visually impaired, so however we act will affect how they think of the blind and visually impaired community. So, I decided at that point I wanted to be positive and appreciative of others. For example, if someone wants to help me, I welcome the help and just thank them even if I could do it myself.

Jim certainly hasn't let his RP stop him from doing what he loves. In his spare time, Jim enjoys fishing, hiking, traveling, cooking, wine tasting, and all kinds of sports. Jim's avid about giving back to others, as he's very involved with their local Parish, St. Susanna Catholic Church. There he volunteers at the food pantry, helps with a twinning Ministry with a sister Parish in Uganda, and participates in men's small groups.

Jim also gives back by spending time helping the Foundation Fighting Blindness raise awareness and funds. Jim attended the first Cincinnati/Northern Kentucky Chapter meeting many years ago, but with a busy career and home life, becoming involved was not a high priority at the time. But about ten years ago, Jim started to become more involved with the local Foundation Chapter, participating in meetings and their VisionWalk, and in 2017, he

joined the Chapter leadership as the Chapter Vice President.

“Having a support system and community like the Foundation to provide knowledge is vital when you have a retinal disease,” says Jim. “It’s so beneficial to be with people that understand you and what you’re going through.”

Executing creative new ways of fundraising for the Foundation comes easy for Jim. In 2017, shortly after his mother passed away, Jim started making her homemade pickle recipe, selling over 350 pints, with all the funds collected going to the Foundation. And in the fall of 2021, Jim and Peggy hosted a wine tasting fundraiser for the Foundation at their house. Jim worked with Glenn Alexander of Sanglier Cellars, who donated all of the wine, and his brother, John, who is a chef, to create a five-course meal for 37 people, raising over \$4,000.

In addition to fundraising, Jim started volunteering with the Foundation’s Professional Outreach team in 2020. Jim’s work with the team helps eye care professionals in the Cincinnati and Northern Kentucky area provide vital resources and information to their patients with retinal diseases to better understand and manage their conditions. Jim’s previous work experience prepared him for this volunteer role, so he was already used to the phone calls and persistence required.

“Because of my experience being diagnosed with RP and being told there was nothing that could be done, I want to make sure other people don’t have to endure that,” says Jim. “I just want to give people the right resources so they know what’s out there to help them. It’s giving people the gift of knowledge, community, and hope.”

Thanks to Jim’s hard work, Luke Lindsell, OD, MD, Jim’s ophthalmologist at the Cincinnati Eye Institute (CEI), has connected the Foundation with many key doctors associated with their practice. Jim orchestrated a Foundation



presentation for CEI’s referral group that provided CME credits for 140 physicians, and now they’re preparing a series of presentations to teach their technicians more about retinal diseases as well. Jim is also planning some Foundation presentations with CABVI in the next few months.

“I’m passionate about helping the Professional Outreach team because once you get a hold of the key people, they always agree they could do better for their patients with retinal diseases,” says Jim. “It’s shocking news to be diagnosed, so it’s fulfilling for me to be able to help someone newly diagnosed have a better handoff. In the end, the more people that hear about the Foundation, the more people get involved. Naturally, this leads to more funds being raised to allow for more research, so it’s a trickle effect.”

Jim’s hopeful his work with the Foundation will give someone newly diagnosed the confidence and information they need to stay positive in their vision loss journey.

“I’m optimistic that there will be some kind of treatment or cure that will help me before I get to the point that I can’t see anything,” says Jim. “It won’t be long before treatments are available for a wide range of people with inherited retinal diseases. It isn’t a question if we as a medical community are capable of finding treatments and cures; it just takes a lot of money and time.”



## IN FOCUS

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