

2022 Annual Report



FOUNDATION **FIGHTING
BLINDNESS**
Together, we're winning.

For over 50 years, the Foundation Fighting Blindness has been fighting to find treatments and cures for people affected by retinitis pigmentosa, macular degeneration, Usher syndrome, and the entire spectrum of blinding retinal diseases. In that time, science has led to brilliant breakthroughs and established many research pathways to pursue.

These promising initiatives wouldn't happen without research funded by the Foundation... research made possible by your generosity. The next research breakthrough to end blinding retinal diseases could be around the corner—but there's still work to be done.

Continue learning more and staying connected with the Foundation by calling **(800) 683-5555** or visiting **www.FightingBlindness.org**.

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A Message from Our Board Chairman & Chief Executive Officer

Dear Friends of the Foundation,

As board chair, I want to extend my thanks to you, our partners in the fight for vision, and introduce to you the 2022 Foundation Fighting Blindness Annual Report. It's a summary of the amazing achievements made possible by the work we fund—all thanks to you and your generosity.

As the science we fund continues to evolve, so does the Foundation. Some significant changes were made in late June when Ben Yerxa, who had served as CEO since 2017, transitioned to assume the permanent CEO position for Opus Genetics, the first spin-off company internally conceived and launched by the RD Fund. Subsequently, the Foundation president and chief operating officer Jason Menzo was named CEO, and Rusty Kelley was appointed managing director of the RD Fund.

On behalf of the board, I thank Ben for his incredible service to the Foundation. He was the right person at the right time for the Foundation, and we are pleased that he will stay close to the organization as he leads Opus Genetics. We all look forward to working with Jason and Rusty in their new roles as they build upon the current direction and strategies to propel the work of each organization forward.

In 2022, we concluded the celebrations marking our 50th anniversary, so Jason and I want to start by reflecting on the impact the Foundation has made over the last half century. We're both so proud of where this

organization has been and where it is going. Today, we aspire to be the undisputed global leader in the inherited retinal disease space. It's a high bar—it means that we have to be credible, we have to know the research and the field better than anyone else and we have to be out there where the conversations are happening. We're confident that our board, staff, and volunteers are up to the challenge.

For proof of the strength of this Foundation today, look no further than the transition from Ben's terrific leadership to Jason, someone we developed within the organization. But our true strength isn't the staff or board, it's the community and the people—the Chapters and folks all over the country and across the globe—that have helped propel us forward. We've had more engagement this past year than ever before, not just in terms of donors but in terms of people who've engaged through our website and social media, participated in our Chapter webinar series, and showed up for VisionWalks.

We attribute that level of engagement to an intentional desire that we have had to reach out at the grassroots level. We've put emphasis on Chapters, on having staff out in the community, and we've invested in Saturday webinars that routinely attract 2,000 participants. It's not a top-down approach. We need the community in order to succeed in what we're doing. We've made an intentional effort to make sure they know that, and they've responded.

Over the last 12 months, there have been a notable number of headlines about clinical

trials that have failed and other challenges in this field. But we prefer to take the long view—this is not easy work. It is hard work, and there are going to be challenges that we meet along the way. But at the end of the day, we're still fighting, and we're still winning.

We're learning from the challenges that were revealed by these unsuccessful trials, and we're putting effort behind using those as a springboard to ensure future clinical trials have a better chance at success. It is clear to us that there's a constant push forward and inertia based on our work. And, of course, the RD Fund is more important now than ever before because of the challenges in the biotech funding environment.

We never lose sight of the fact that passionate donors and supporters like you make it all possible. We had more donors give to the Foundation than ever before. We did it by having a lot of people engaged and giving. We surpassed our goal for

corporate giving by double digits, and we plan to build on that success in the future.

In conjunction with our 50th anniversary, the Victory for Vision campaign sought to raise an additional \$50 million above our annual fundraising. The campaign was an undisputed success, thanks to friends like you.

Today, we're funding more research than ever before. Companies in our RD Fund portfolio continue to thrive despite a difficult environment, and we have one of the largest patient registries in the world for individuals affected with an inherited retinal disease.

We turn our focus now to the next several years and beyond. With a committed and energetic staff and board, a passionate army of grassroots volunteers, and, of course, your continued support, we are hopeful that together, we will have victory for vision.

With gratitude,



David Brint
Chair, Board of Directors



Jason Menzo
Chief Executive Officer

Research Progress for 2022

Clinical development for inherited retinal disease (IRD) treatments continued to advance impressively during 2022. Foundation funding continued to play a leading role in advancing the field, especially in moving emerging therapies into and through clinical trials. More than 40 clinical trials are underway for potential treatments for IRDs and dry age-related macular degeneration (dAMD). Many more emerging therapies are poised to move into human studies soon. This fiscal year's research highlights include:

MeiraGTx and Janssen Launch Phase 3 XLRP Gene Therapy Clinical Trial

MeiraGTx and Janssen Pharmaceuticals launched LUMEOS, their Phase 3 gene therapy clinical trial for males and females, three years of age and older, with X-linked retinitis pigmentosa (XLRP) caused by mutations in the gene RPGR. The trial is taking place at several sites in the US and Europe. The companies previously reported that the XLRP gene therapy had a beneficial effect on vision in their Phase 1/2 clinical trial. MeiraGTx's gene therapy is designed to deliver functional copies of the RPGR gene to the retina with the goal of improving or preserving vision.

AGTC Plans Launch of Phase 2/3 Clinical Trial for XLRP Gene Therapy

Applied Genetic Technologies Corporation (AGTC) began planning the launch of VISTA, its Phase 2/3 clinical trial for males between 13 and 50 years of age with X-linked retinitis pigmentosa (XLRP) caused by mutations in the gene RPGR. During 2022, the company reported additional vision improvements from its ongoing Phase 1/2 clinical trial and in its expanded Phase 2 SKYLINE trial at eight sites in the U.S.

Apellis Files for FDA Approval of its Dry AMD Drug

Apellis announced that combined results from two Phase 3 clinical trials, DERBY and OAKS, showed that its drug APL-2 (pegcetacoplan) reduced the progression of geographic atrophy (GA), the advanced form of dry age-related macular degeneration (dAMD). In trials, the drug was administered monthly or bimonthly into the vitreous, the soft gel in the middle of the eye. The company submitted a New Drug Application (NDA) for APL-2 to the U.S. Food and Drug Administration (FDA) in the first half of 2022 and expects a response from the FDA in the first quarter of 2023.

Iveric Bio's Zimura for Advanced Dry AMD Meets Endpoint in Second Phase 3 Clinical Trial

Iveric Bio reported that its emerging treatment Zimura[®] met the primary endpoint in the GATHER2 Phase 3 clinical trial for people with geographic atrophy (GA), the advanced form of dry AMD. Injected monthly into the vitreous, the soft gel in the middle of the eye, Zimura reduced the growth of the lesions associated with GA. Iveric Bio plans to file a NDA with the FDA by the end of the first quarter of 2023.

Foundation's RD Fund Invests in SalioGen Therapeutics, Developer of Novel Gene Coding Technology for Treating Inherited Retinal Diseases

The RD Fund (Retinal Degeneration Fund), the venture philanthropy arm of the Foundation Fighting Blindness, has invested in SalioGen Therapeutics, a biotechnology company developing therapies for a broad range of conditions, including IRDs, using its novel Gene Coding™ technology. The company is currently developing research- and preclinical-stage programs and aims to launch future clinical trials for treatments for Stargardt disease (ABCA4), Usher syndrome, RP25 (EYS), and RP1.

SalioGen's Gene Coding platform works by adding new genomic code to turn on, off, or modify function of new or existing genes. Gene Coding is accomplished by SalioGen's Exact DNA Integration Technology™ (EDIT™), which is based on mammal-derived genome engineering enzymes called Saliogase™. Saliogase seamlessly inserts new DNA of any size into precise, defined genomic locations.

Kiora Launches Clinical Trial in Australia for Vision-Restoring Small Molecule for RP Patients

Kiora Pharmaceuticals has launched a clinical trial for KIO-301, its emerging small-molecule therapy to restore vision in people with advanced retinitis pigmentosa and potentially other retinal conditions. Known as the ABACUS study, the Phase 1B clinical trial is taking place at The Royal Adelaide Hospital in Adelaide, South Australia, and enrolled its first patient in the fourth quarter of 2022.

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

Clinical Trial Pipeline

Select Inherited Retinal Diseases and Dry AMD Clinical Trials: 42 Trials

Below includes many of the clinical trials of emerging therapies underway for inherited retinal diseases and dry age-related macular degeneration. For more details on these trials, visit: ClinicalTrials.gov or FightingBlindness.org

GENETIC THERAPIES (GENE TARGET)

Achromatopsia (CNGB3) – AGTC Phase 1/2
 Achromatopsia (CNGB3) – MeiraGTx/Janssen Phase 1/2
 Achromatopsia (CNGA3) – MeiraGTx/Janssen Phase 1/2
 Achromatopsia (CNGA3) – Tubingen Hosp..... Phase 1/2
 AMD-dry (CFI) – Novartis Phase 2
 Batten disease (CLN5) – Neurogene Phase 1/2
 Choroideremia (REP1) – 4DMT Phase 1/2
 Choroideremia (REP1) – Tubingen 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) – Tubingen Hosp..... Phase 1/2
 Retinoschisis (RS1) – NEI..... Phase 1/2
 X-linked RP (RPGR) – AGTC..... Phase 3
 X-linked RP (RPGR) – MeiraGTx/Janssen..... Phase 1/2
 X-linked RP (RPGR) – 4DMT Phase 1/2

RNA/OTHER THERAPIES (MECHANISM)

AMD-dry (CB inhibitor) – Ionis..... Phase 2
 LCA (CEP290, AON) – ProQR..... Phase 2/3
 RP, Usher, others (optogenetic) – Bionic Sight Phase 1/2
 RP, Usher, others (optogenetic) – GenSight..... Phase 1/2
 RP, Usher, others (optogenetic) – Nanoscope..... Phase 2
 Stargardt disease (optogenetic) – Nanoscope Phase 2
 Usher syndrome 2A (AON) – ProQR..... Phase 2/3

CELL-BASED THERAPIES (CELL TYPE)

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
 Stargardt disease (RPE) – Astellas..... Phase 1/2

SMALL MOLECULES (MECHANISM)

AMD-dry (C3 inhibitor) – Apellis Phase 3
 AMD-dry (C5 inhibitor) – Iveric bio..... Phase 3
 RP (NAC-anti-oxidant) – Johns Hopkins Phase 2
 RP (methotrexate) – Aldeyra Phase 2
 RP (small molecule) – Endogena..... Phase 1/2
 RP (small molecule, photoswitch) Kiora..... 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

NOTE:

Some trials listed may have been paused and/or the sponsors are seeking partners to continue their trials.



Foundation Commits More Than \$15 Million in New Funding to 23 Promising Research Projects for Blinding Retinal Disease Treatments & Cures

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.

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.

“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.”

Types of Awards

The **Translational Research Acceleration Program (TRAP) awards** accelerate the movement of preclinical research toward an Investigational New Drug filing and into clinical trials to provide a robust and diverse pipeline of potential therapies to fight inherited retinal degenerations and dry age-related macular degeneration.

Individual Investigator Research Awards are designed to concentrate research in areas with the greatest potential to move toward treatments and cures for inherited orphan retinal degenerative diseases and dry age-related macular degeneration.

The **Research Core Award** provides funding support to individuals or teams striving to identify, develop, characterize and support relevant large animal models of IRD or dry age-related macular degeneration (AMD) that are poorly modeled in rodents for which canine models do not currently exist.

Program Project Awards fund studies that are too large or technically complex for a single investigator to undertake in a reasonable amount of time and to address current knowledge and/or therapeutic gaps.

The **Free Family Age-Related Macular Degeneration (AMD) Award** funding strives to find solutions for early, dry AMD.

The **Career Development Program** supports physicians' and physician-scientists' career development through a multi-level, tiered approach across the duration of their careers. Each level represents a new "stage" in the career progression of a physician or physician-scientist, at a point when they can choose a clinical and/or research direction. The Foundation Fighting Blindness' career development program includes funding support for clinicians and medical residents in veterinarian studies in retinal degenerations.



New Grants

Translational Research Acceleration Program (TRAP)

Rui Chen, PhD – \$899,820

Baylor College of Medicine

“Retinal regeneration through an epigenetic therapy”

Mireca – \$989,000

“Towards the clinical translation of mutation-independent treatment for hereditary retinal degeneration”

BioJiva – \$1,446,827

“Testing the efficacy of a deuterated form of DHA as a mutation independent therapy in retinitis pigmentosa”

THE DIANA DAVIS SPENCER TRANSLATIONAL
RESEARCH ACCELERATION AWARD

James Hurley, PhD – \$717,724

University of Washington

“Simulation of fatty acid oxidation to diminish drusen in AMD”

William Beltran, DVM, PhD – \$1,480,695

University of Pennsylvania

School of Veterinary Medicine

“Characterization and mitigation of ocular inflammation from AAV gene therapies”

Marius Ader, PhD – \$883,554

Technische Universität Dresden

“Reconstruction of the RPE-photoreceptor interface via sequential transplantation of iPSC-derived RPE and photoreceptors”

Individual Investigator Research Awards

Karl Wahlin, PhD – \$300,000

University of California, San Diego

“Endogenous repair and regeneration in a human 3D retinal organoid model of Leber congenital amaurosis”

Kinga Bujakowska, PhD – \$300,000

Massachusetts Eye and Ear,
Harvard Medical School

“Exon skipping as an approach to treating EYS-associated retinitis pigmentosa”

Vadim Arshavsky, PhD – \$300,000

Duke University

“Activation of cellular proteostasis as an approach to treat inherited retinal degenerations”

Abigail Jensen, PhD – \$300,000

University of Massachusetts, Amherst

“Identifying mechanisms of Stargardt disease from zebrafish models”

Deepak Lamba, PhD – \$300,000

University of California, San Francisco

“Cone-dominant tree shrews to model human cone dystrophies”

Uwe Wolfrum, PhD – \$300,000

Johannes Gutenberg University Mainz

“Establishment and characterization of a pig model for Usher syndrome type 1B”

FUNDING PARTNER: SAVE SIGHT NOW

Rinki Ratnapriya, PhD – \$300,000

Baylor College of Medicine

“Systematic and scalable analysis of genomic data to identify novel inherited retinal degenerative disease genes and mutations”

Research Core Awards

Mark Pennesi, MD, PhD – \$75,000

Oregon Health & Science University

“Modeling Usher syndrome type 1B and 2A using human retinal organoids”

FUNDING PARTNER: SAVE SIGHT NOW

Maureen McCall, PhD – \$65,830

University of Louisville

“Exploring development of a pig model for CRB1 disease”

Program Project Awards

Isabelle Audo, MD, PhD

Fondation Voir et Entendre

Aziz El-Amraoui, PhD

Institut Pasteur

Deniz Dalkara, PhD

Fondation Voir et Entendre

\$2,317,150

“Fighting Usher syndrome type 1B: disease pathogenesis and treatment solutions”

FUNDING PARTNER: SAVE SIGHT NOW

Alison Hardcastle, PhD

UCL Institute of Ophthalmology

Susanne Roosing, PhD

Radboud UMC, The Netherlands

Michael Cheetham, PhD

UCL Institute of Ophthalmology,
London, UK

\$2,500,000

“Investigating the novel disease mechanism for autosomal dominant RP17 and exploring therapeutic approaches”

Free Family Age-Related Macular Degeneration (AMD) Award

Catherine Bowes Rickman, PhD

Duke University

John Flannery, PhD

University of California, Berkley

\$600,000

“Preclinical Testing of Complement Factor H Gene Augmentation Therapy to Treat Dry AMD”

Career Development Awards

Thomas Wubben, MD, PhD – \$375,000

University of Michigan

“Metabolic uncoupling and AMD: assessing the bioenergetic crisis of the outer retina”

Lesley Everett, MD, PhD – \$500,000

Oregon Health & Science University

“Investigation of the role of TUBGCP4 and TUBGCP6 in the development of the retinal vasculature”

THE DIANA DAVIS SPENCER CAREER DEVELOPMENT AWARD

Priya Gupta, MD – \$65,000

Duke University

“Determination of Genetic Causality in Elusive Unsolved IRD Cases”

CLINICAL RESEARCH FELLOWSHIP AWARD (CRFA)

Alessia Amato, MD – \$65,000

Università Vita-Salute San Raffaele

“Characterization and optimization of dark-adapted two-color fundus perimetry in patients with inherited retinal disease”

CLINICAL RESEARCH FELLOWSHIP AWARD (CRFA)

Hamzah Aweidah – \$65,000

University of Pittsburgh,

University of Pittsburgh Medical Center

“PRPF31-associated retinitis pigmentosa: Clinical and genetic characterization in humans and gene augmentation therapy in a non-human primate model”

CLINICAL RESEARCH FELLOWSHIP AWARD (CRFA)

Snapshot of Our Grants and Awards

These **new** research awards are selected through a rigorous review process conducted by the Foundation’s Scientific Advisory Board – composed of preeminent, international clinical and scientific leaders in ophthalmology and vision research.

July 2021 – June 2022 (Fiscal Year 2022)

In FY2022, new research awards added to our existing research portfolio:

\$15,145,600

126

Letters of intent (LOI) reviewed across all funding opportunities

52

Applications reviewed across all funding opportunities

6

Foundation-sponsored or co-sponsored meetings and workshops

2

Study sections conducted

FY22 Funding Opportunities

New Awards Granted



Clinical Research Fellowship Award
(4 Apps)



3 Clinical Research Fellowship Awards
(\$195,000)



Career Development Award
(7 Apps)



2 Career Development Awards
(\$875,000)



Free Family Initiative in AMD
(23 LOIs/ 7 Apps)



1 Free Family AMD Award
(\$600,000)



Program Project Award
(2 LOIs/2 Apps)



2 Program Project Awards
(\$4,817,150)



Translational Research Acceleration Award
(48 LOIs/14 Apps)



6 Translational Research Acceleration Awards (\$5,400,000)



Individual Investigator Research Award
(53 LOIs/18 Apps)



7 Individual Investigator Research Awards (\$2,100,000)

- **Clinical Innovation Award**
(folded into Individual Investigator Research competition)



2 Resource Awards
(\$140,830)



2 Clinical Consortium Natural History Studies

The awards included in this report are those approved for funding during FY22. The start date of these awards varies and could be either FY22 or FY23.

Scientific Advisory Board

The Foundation Fighting Blindness Scientific Advisory Board is comprised of the world's leading retinal experts who provide insight on research and clinical advancements, and review research grant applications.

Chair

Jacque Duncan, MD

Professor and Interim Chair, Ophthalmology
Beckman Vision Center
University of California, San Francisco

Vice Chairs

Catherine Bowes Rickman, PhD

George and Geneva Boguslavsky Distinguished
Professor of Eye Research
Duke University Medical Center

Stephen Daiger, PhD

TS Matney Professor,
Environmental and Genetic Sciences
Human Genetics Center
University of Texas Health Science Center

Frederick Ferris, III, MD

Ophthalmic Research Consultants, LLC

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Associate Director, Helen Wills Neuroscience
Institute
University of California, Berkeley

José-Alain Sahel, MD

Professor and Chairman, Ophthalmology
University of Pittsburgh School of Medicine

Marco Zarbin, MD, PhD

Professor and Chair, Institute of Ophthalmology
and Visual Science
Rutgers-New Jersey Medical School

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and Ophthalmology
School of Veterinary Medicine
University of Pennsylvania

Bela Anand-Apte, MBBS, PhD

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Cleveland Clinic Foundation

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Associate Professor of Ophthalmology
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Isabelle Audo, MD, PhD

Group Leader, Department of Genetics
Institut de la Vision
Consultant
Reference Centre for Rare Diseases
at CHNO, Quinze-Vingts

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Shiley Eye Center
University of California, San Diego

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School of Veterinary Medicine
University of Pennsylvania

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Professor, Ophthalmology
and Visual Sciences
Moran Eye Center, University of Utah

David Birch, PhD

Director, Rose-Silverthorne Retinal
Degenerations Laboratory
Retina Foundation of the Southwest

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Emory University School of Medicine

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Johns Hopkins University School of Medicine

Robert B. Hufnagel, MD, PhD

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National Eye Institute

Elise Héon, MD

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SickKids
Professor, Department of Ophthalmology
University of Toronto

Leslie Hyman, PhD

Vice Chair for Research
*The Vickie and Jack Farber Vision Research Center
at Wills Eye Hospital*

Thomas D. Duane Endowed Chair
Professor and Vice Chair of Research,
Ophthalmology
*Sidney Kimmel Medical College at
Thomas Jefferson University*

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*Duke University Medical Center
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FRANZCO**

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*Michigan Medicine Ophthalmology Retina Clinic
W. K. Kellogg Eye Center*

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University of Washington

Tiansen Li, PhD

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National Institutes of Health*

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Goldis Malek, PhD

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Maureen Neitz, PhD

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University of Washington

Gary Novack, PhD

President
PharmaLogic Development, Inc.
Clinical Professor of Ophthalmology
University of California, Davis

Mark Pennesi, MD, PhD

Professor of Ophthalmology,
School of Medicine
Division Chief, Ophthalmic Genetics
*Casey Eye Institute,
Oregon Health & Science University*

**Simon Petersen-Jones, DVM,
PhD, DECVO**

Professor, Department of
Small Animal Clinical Sciences
*Michigan State University
College of Veterinary Medicine*

Eric Pierce, MD, PhD

William F. Chatlos Professor, Ophthalmology
*Massachusetts Eye and Ear Infirmary
Harvard Medical School*

Thomas Reh, PhD

Director, Neurobiology and Behavior
Department of Biological Structure
University of Washington School of Medicine

Bärbel Rohrer, PhD

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Medical University of South Carolina

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University of Basel

Johanna Seddon, MD, ScM

Professor of Ophthalmology
Director of Retina, Director of Macular
Degeneration Center of Excellence
University of Massachusetts Medical School

Janet Sparrow, PhD

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of Pathology and Cell Biology
Columbia University

Janet Sunness, MD

Medical Director, Hoover Low
Vision Rehabilitation Services
Greater Baltimore Medical Center

Debra Thompson, PhD

Professor, Ophthalmology and Visual Sciences
Kellogg Eye Center, University of Michigan

Douglas Vollrath, MD, PhD

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Stanford University School of Medicine

David Williams, PhD

Laboratory Director, Professor
Director, Jules Stein Eye Institute
University of California, Los Angeles

Michael Young, PhD

Associate Professor, Ophthalmology
Harvard Medical School
Schepens Eye Research Institute

Paul Yang, MD, PhD

Associate Professor of
Ophthalmology, School of Medicine
Casey Eye Institute
Oregon Health & Science University

Donald Zack, MD, PhD

Co-Director,
*Johns Hopkins Center for Stem Cells and Ocular
Regenerative Medicine*
Professor, Ophthalmology
*Wilmer Eye Institute, Johns Hopkins
University School of Medicine*

Emeritus**Robert E. Anderson, MD, PhD****Jean Bennett, MD, PhD**

Eliot L. Berson, MD Deceased
May 9, 1937 – March 19, 2017

Dean Bok, PhD**John E. Dowling, PhD****Debora B. Farber, PhD****Gerald A. Fishman, MD****Morton F. Goldberg, MD****Gregory S. Hageman, PhD****William W. Hauswirth, PhD****Joe G. Hollyfield, PhD****William J. Kimberling, PhD**

Alan M. Laties, MD Deceased
February 8, 1931 – December 26, 2021

Matthew M. LaVail, PhD**Vincent H. L. Lee, PhD****Roderick R. McInnes, OC, MD, PhD, FRSC****Edwin Stone, MD, PhD****Russell N. Van Gelder, MD, PhD****Richard G. Weleber, MD****Andreas Wenzel, PhD**

Developments of the My Retina Tracker[®] Registry and Genetic Testing Program

The Foundation's no-cost genetic testing program and the My Retina Tracker[®] Registry for people with inherited retinal diseases (IRDs) continued to expand during the fiscal year 2022. Since its launch in 2017, more than 11,000 people with IRDs have received no-cost genetic tests through our program, which screens for mutations in inherited retinal disease genes using a comprehensive 355-gene panel. The Foundation is committed to patient privacy and never shares personally identifying data. No-cost genetic counseling provided by InformedDNA helps patients and families understand what the testing results mean and can guide them to the research underway that is relevant to their conditions.

More than 20,000 people are now active participants in the Registry, which connects patients and researchers, including therapy developers recruiting for clinical trials, while protecting patient privacy. The large cohort of genetically tested individuals has become increasingly valuable as a source for deidentified research data. The Foundation's Registry team makes frequent contact with Registry members to provide research updates, invite their participation in workshops, and recruit for clinical trials.

"This year, the Registry team focused on member outreach and engagement," said Todd Durham, PhD, senior vice president of clinical and outcomes research at the Foundation. "Over this last year, we contacted two-thirds of our members by email and spoke with over 1,300 of

them by phone. We are committed to maintaining long-term engagement with our Registry members to make sure they can connect with research opportunities as they arise. Our Registry staff are available to register new members, update profiles, and answer questions."

To learn more about our Registry, visit: MyRetinaTracker.org

FOUNDATION FIGHTING BLINDNESS



The Foundation greatly appreciates the support of its partners for helping drive the growth and success of both the Registry and the genetic testing program:

4DMT	InFocus Clinical Research
Anylam Pharmaceuticals	InformedDNA
Applied Genetic Technologies Corporation (AGTC)	Janssen
Atsena Therapeutics	MeiraGTx
Blueprint Genetics	Nixon Visions Foundation
Coave Therapeutics	Ocugen
Editas Medicine	ProQR Therapeutics
The George Gund Foundation	PTC Therapeutics
Hope in Focus	Spark Therapeutics



PROFESSIONAL OUTREACH:

Empowering Eye Care Professionals to Deliver Better Care and Hope to Retinal Disease Patients

For nearly four years, the Professional Outreach department has been educating eye care professionals throughout the U.S. about IRDs and the Foundation's many resources for patients and families with IRDs. These valuable resources include no-cost genetic testing, the My Retina Tracker® Registry, research and disease information, educational events, and connection to local chapters.

The team's overarching goal is to help eye care professionals provide a hopeful and informed path forward for their patients with inherited retinal diseases and age-related macular degeneration. Also, by ordering no-cost genetic testing and counseling through the Foundation, eye doctors are able to deliver an accurate diagnosis to patients and do so quickly, often in four to six weeks.

Since its inception, the department has developed a network of more than 1,400 U.S. partners which include: retinal specialists, optometrists, low vision specialists,

and a variety of professional academies, associations, schools, and colleges.

In 2022, the department launched a four-course training program to empower volunteers in local Foundation Chapters to educate eye care professionals in their communities about the Foundation's patient resources. More than 90 volunteers participated in the program.

The team also hosted 44 webinars for its partners as well as two continuing education courses for eye care professionals (offering CME/COPE credits):

"A Review of Gene Therapy for Inherited Retinal Disease," delivered by Paul Yang, MD, PhD, Casey Eye Institute, Oregon Health & Science University.

"A Review and Comparison of the Different Forms of Age-Related and Inherited Macular Degenerations," delivered by Marco Zarbin, MD, PhD, Rutgers-New Jersey Medical School.

Impact Study

The Foundation partnered with ClearView Healthcare Partners to evaluate the impact of its funding and resources since 2005 on the clinical understanding and development of novel therapies for inherited retinal diseases (IRDs). Below are 11 key take-aways.



The Foundation has played a major role in the development of 88% of treatments in clinical trials for the leading retina diseases.



89% of the recipients who have received a Career Development Award from the Foundation have continued working in the retinal disease field.



Later-stage funding from the Foundation has resulted in 14 programs entering a clinical stage.



Foundation-funded projects have developed 38% of the large non-rodent animal models to help better understand the cause of blinding retinal diseases.



More than 10% of people with blinding diseases are registered in the Foundation's My Retina Tracker Registry® – the largest retinal disease patient database connecting people to relevant clinical trials.



Since 2005, projects funded by the Foundation have helped to identify 40% of the genes that cause blinding diseases.



Since 2005, the Foundation has awarded 440 grants for retinal disease research to 227 individuals, resulting in more than 12,000 published research articles.



Providing free genetic testing has increased the number and diversity of people with a blinding disease who know their genetic mutation.



Foundation-led natural history studies have helped to identify additional measures used to determine the success of clinical trials – including one that led to the first FDA-approved gene therapy for the eye or any inherited disease, LUXTURNA™.



Foundation-sponsored research and clinical studies were instrumental in identifying key measures used to inform clinical trial designs.



The advancement of optogenetics has been guided by investments of the Foundation and the RD Fund.

Community Highlights

VISIONS 2022 and Lulie's Light Awards

At the VISIONS 2022 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 provide access to local resources to guide individuals through their personal journeys. Lulie's Light Award will annually recognize the work and impact of the Chapters network around the nation. The following Chapters were the inaugural Lulie's Light Awardees:

COMMUNITY CHAMPION AWARD



Bay Area
Chapter President
Eric Zankman

PATHMAKER AWARD



Los Angeles
Chapter President
Jessie Wolinsky

GUIDING VISION AWARD



Jacksonville
Chapter President
Adriann Keve

These Chapters, as well as all our other Chapter leaders and members, are generous with their time and talents, and they bring light and vision to many incredible efforts that impact their local communities.

Community Connections

Our Chapters are focusing on the impact that networking can have on those in our communities. Our Los Angeles Chapter conceptualized and piloted the first Community Connections call. This event provided a safe space for those impacted by low vision to come together to share resources, experiences and to meet others who have gone through similar situations as them. We have since expanded these calls nationwide and are hosting breakout rooms based on vision loss type and location. We've heard a ton of positive feedback from our members, and we are excited to continue to host our Community Connections calls to unify our supporters across the Chapters network.

Raising Our Sights Fundraising Program

As our Chapters continue to grow, so does the impact that the local leaders have on our mission. **Alec Yeaney** created the Blind Ambition Challenge fundraiser in support of the Foundation. This *Raising Our Sights* fundraiser brought in over **\$7,000** and helped others better understand what it is like to live with vision loss. Alec challenged people to play cornhole, paint their nails, or take part in another task while being blindfolded and posting their results on social media. His goal was to raise awareness about vision loss, all while helping to raise funds for research to find treatments and cures for blinding diseases. To learn how to start your own *Raising Our Sights* fundraiser, reach out at: **Chapters@FightingBlindness.org**

Hope from Home: A United Night to Save Sight

For a second year, the Foundation hosted Hope from Home: A United Night to Save Sight as a national virtual gala, raising over **\$600,000**. Joining us on March 6, 2022, was celebrity emcee Wayne Brady who also performed a unique musical improv set with a live audience. Jazz artist Katriona Taylor and Britain's Got Talent semi-finalist Sirine Jahangir added their unique stories and performances to the evening. Nearly 500 households logged in to experience this virtual gala, chaired by Foundation board members and leaders **Jonathan Steinberg, MD**, and **Alice Cohen, MD**.

VisionWalks

The Foundation hosted 37 walks across the country this past fiscal year, raising over **\$3.4 million** and attracting over 8,000 attendees and 723 teams. These fun, family-friendly events bring together hundreds of teams and thousands of walkers as we take steps toward treatments and cures for blinding retinal diseases.



A blindfolded participant painting the nails of the girl next to him.



*Cleveland Chapter President **Paula Dubecky** and her family posing with a VisionWalk frame that has the Foundation and VisionWalk logos on the top and #VisionWalkStrong on the bottom.*



*Teams "Wild Bunch," in blue, captained by **Carol Edwards** and "Jackson's SpEYEdey Squad," in red, captained by **Jacklyn Peterson**, showing their spirit at the 2022 DC Metro VisionWalk.*

Night for Sight

On May 20, 2022, the Foundation's Night for Sight gala returned in-person to New York City with co-chairs and Foundation board directors **Evan Mittman** and **Jason Ferreira**, celebrity emcee Heather Thomson, and auctioneer Mark Farrell. Thanks to the generosity of so many, Night for Sight raised over **\$480,000**. Guests at Night for Sight enjoyed world-class entertainment from popular rock band X Ambassadors, who also shared their story of founding member Casey Harris' vision loss. Through Night for Sight, the Foundation celebrated the incredible contributions of the Beacon Society: **Allegiance Retail Services, Steve Bokser, Samuel Collado, Rudy Fuertes, Jason Ferreira, Jill Granoff, Bradford Manning, Bryan Manning, Evan Mittman, Porky Products, and John Sharko.**

Triangle Night to Save Sight

On June 2, 2022, the Foundation celebrated a new event in Raleigh, North Carolina, Triangle Night to Save Sight. This experiential dinner featured Ashley Christensen, recipient of the 2019 James Beard Outstanding Chef Award, who conducted a cooking demonstration with step-by-step instructions and tastings for guests to enjoy – all while raising critical funds and awareness to further the Foundation's mission. Attendees from all over the Triangle joined together for a night of delicious food and drinks and raised over **\$80,000**.



From left to right: Khadija Bari, X Ambassadors' Casey Harris, and Lachi all holding their white canes posing in front of the Foundation backdrop next to him.



Ashley Christensen giving a cooking demonstration at Triangle Night to Save Sight Dinner.

Melissa and April holding hands and sitting with their backs to each other on a workout mat in the gym.



BEACON STORY:

Fearless Sister Duo Finding Hope

Sisters April LuFriu and Melissa Escobio are best friends who do everything together. They live with their families in Tampa, Florida, enjoy traveling to new places, and are fearless about new experiences. They also both have retinitis pigmentosa (RP).

In 1989, Melissa was diagnosed with RP at the age of 21. Melissa was the first in their family to receive this diagnosis, so she felt totally blindsided by the news. So in 2006, Melissa and April decided to seek out others affected with blinding diseases and found the Foundation Fighting Blindness. The sister duo created & formed the Tampa Bay Chapter for the Foundation Fighting Blindness and April serves as the president and Melissa serves as the vice president.

Then, in 2010, April, along with her ten-year-old son Brandon, and six-year-old daughter Savannah, were all diagnosed with RP, specifically X-linked RP (XLRP).



Melissa and April hiking in Sedona, Arizona.

“It was devastating to find out my children are affected, but I always had my sister to support me,” says April. “And I had the Foundation to help guide me too, so I never felt alone.”

April’s RP is mild and doesn’t affect her day-to-day vision, while her children’s and Melissa’s RP are progressing more quickly. So to help April cope, she decided to start competing in pageants, which she used to do when she was young adult.

At first, it wasn’t easy, but April wanted to use the platform to help raise awareness and funds for diseases like RP. And

in 2011, April won the Mrs. Florida America pageant. Six weeks later, she competed in the Mrs. America pageant and won again. Following that was Mrs. World 2012, where she won yet again.

“I had the right purpose, and I just stayed true to myself,” says April. “All I did was talk about my kids, blindness, and supporting the community, which seemed to resonate with the judges. I’m so grateful for the opportunities I had during my reign to spread awareness, and I couldn’t have done it without my family by my side.”

It’s clear April is a go-getter, and with Melissa by her side, they’re both unstoppable and adventurous when trying new things. They recently flew in a helicopter with no doors over New York City and hiked in Sedona, Arizona, and April helps to narrate to Melissa what she may not be able to see herself.

“You can’t let your diagnosis stop you, you have to just keep going, and you can still live a full life,” says Melissa. “I never look down on my diagnosis. We all have our moments, it can be upsetting, but I don’t dwell on it, and I keep living my dreams.”

Melissa’s risk-taking attitude also led her to participate in a stem cell clinical trial at the University of California, Irvine, in 2018.

“I’m so grateful I was able to be a part of this trial, and it was a wonderful experience,” says Melissa. “It was a lot, though, and I had some side effects to the medications, so I decided not to go forward with my left eye. But I see a slight improvement in my right eye compared to the left, and the progression seems to have slowed.”

April’s son Brandon is also currently participating in the AGTC gene therapy clinical trial for XLRP. Brandon’s first eye surgery was in February 2020, and

he is now being monitored. Melissa and April found out about both trials through the Foundation Fighting Blindness.

“The Foundation got our foot in the door,” says April. “We’re daring to be pioneers and jump in. You can’t live in fear, and you just have to trust the science. And we’ve gotten so much hope from the Foundation.”

In the last year, April and Melissa have become the Foundation’s Tampa Bay Chapter President and Vice President. On June 9, 2022, they helped to launch a brand-new event called **Tampa Wine & Dine for Sight**. This event took place at the Tampa Wine Room, and marked the Foundation’s first in-person event in Tampa in over seven years, raising over **\$106,000** for the Foundation.

“RP has made me acknowledge all the great things in life and not overlook the simple things we take for granted,” says April. “I feel like my life has a purpose, thanks to RP. And even though it’s a tough road, I’ve learned more gratitude, strength, and humility.”



Melissa and April after giving their speeches at Tampa Wine & Dine for Sight.

A Message from Our *Victory for Vision* Co-Chairs

In January of 2021, the Foundation launched the *Victory for Vision* campaign to invest an additional \$75 million in sight-saving research—research that is leading to treatments and cures. We're pleased and proud to report on the progress of the *Victory for Vision* campaign. Because of your generosity, we've already reached a comprehensive total of \$65,016,000 (at the time of going to press).

You've heard it said before, but it bears repeating—supporters like YOU are key to this kind of success. To all those who have given or volunteered, please accept our sincere thanks.

The question is no longer if we will win, but how fast we will win. We need you now, more than ever, to provide the funds for the breakthrough research and innovative science that results in treatments and cures.

Your investment fuels a winning team: the best scientists, the brightest researchers, and the world's top innovators.

Please consider joining us and nearly 200 other givers who have stepped up to join the *Victory for Vision* campaign. Every person and every gift counts.

With gratitude,

Marsha Link
Co-chair

Robert Heidenberg
Co-chair

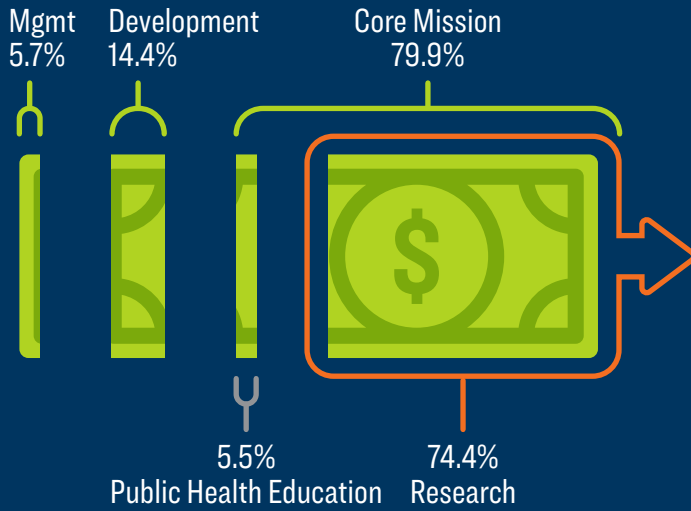
David Brint
Co-chair

Foundation Fighting Blindness and Nixon Visions Foundation Collaborate to Combat Retinal Diseases

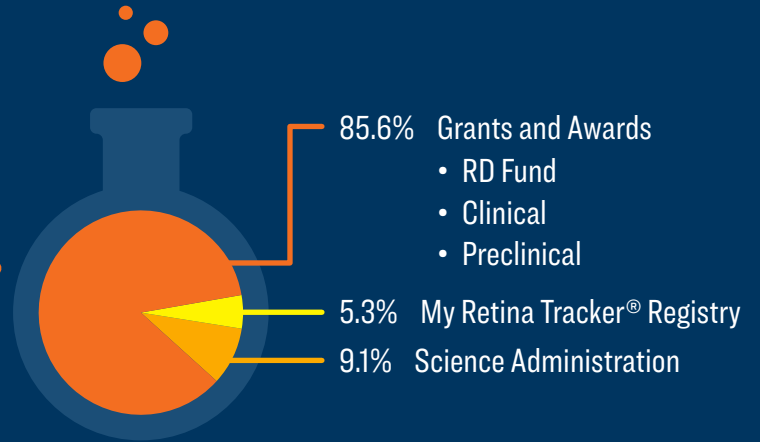
The Foundation is thrilled to be collaborating with the Nixon Visions Foundation and the University of California San Diego on the Nixon Visions Foundation Inherited Macular Dystrophy Program. The Program will provide funding for six early translational research projects over three years for the development of new therapies that could treat inherited macular dystrophy, including visual impairment related to mutations in the PRPH2 gene. In coordination with the Nixon Visions Foundation, the Foundation will build awareness in the inherited retinal disease community about PRPH2 mutations and their effect on blindness.

Where Does the Money Go?

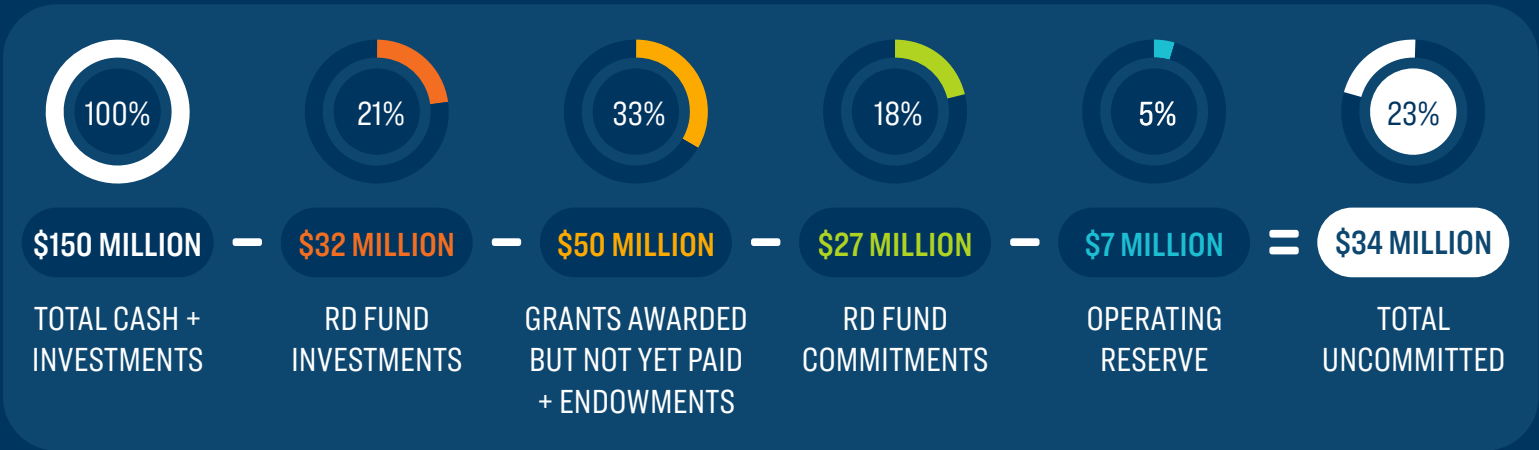
DONATION ALLOCATIONS



RESEARCH BREAKDOWN



SOLID BALANCE SHEET – AGGRESSIVE SPENDING



A Message from Our Treasurer

On behalf of the board and staff of the Foundation, I want to thank you for your support. As a donor myself, and having completed my second year as treasurer, I can say to you with confidence that every effort is made to ensure the responsible handling of your donations.

I am pleased to introduce the statement of activities and financial position for the fiscal year ending June 30, 2022, which demonstrates the Foundation's commitment to fiscal responsibility and focus on funding as much impactful research as possible. The total revenue came in at over \$35 million this fiscal year. We deployed \$27.4 million towards research, spent \$2.7 million on public health and education, and incurred fundraising and management expenses of \$10 million. We completed the fiscal year with assets of approximately \$165 million, which included over \$158 million in commitments to scientific research through donor-restricted funding for grants, endowments, board restrictions, and the RD Fund.

Compared to our budget, our major gifts were greater than anticipated, and our event revenue fell a bit short of expectations, with several planned events being canceled or delayed due to the continued impact of the pandemic. We were, however, encouraged that events revenue continued to climb back toward pre-pandemic levels and that the shortfall versus plan was more than offset by the continued success of fundraising in the *Victory for Vision* campaign.

Our Chapters are growing, thanks in part to "Lulie's Next Chapter for Light & Vision," and they continue to be a critical aspect of our efforts. For many people, the face of the Foundation is the local Chapter, and each Chapter is a tool for

engagement and fundraising. Every dollar matters, and every donor matters.

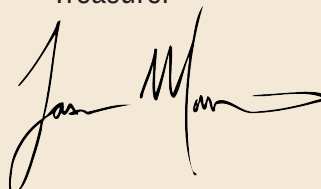
I joined the Foundation through the St. Louis Chapter when my young son, Jack, was diagnosed with a blinding retinal disease. Today, Jack is a sophomore at Brown University. He struggles with peripheral vision and night blindness, but he is thriving, and his vision is currently stable. He is not involved in any treatment or trial, but we remain optimistic as the field progresses.

My belief—and the reason I support the Foundation as opposed to a group solely focused on his gene—is that in this field, a rising tide lifts all boats. By supporting the Foundation and focusing not just on the disease-causing gene affecting our son, I think there's a far greater likelihood that there will ultimately be a solution that will benefit our son. Having an army of scientists working across the field will advance things faster and farther than a much more limited, narrow approach.

We are at the tipping point of what I believe are major breakthroughs that will move the needle for many people. It is only a matter of time before progress that impacts a lot of people is made. None of it would be possible without your passion, commitment, and generosity. Thanks for all you do and for trusting us to make the best use of your gifts. The Foundation prioritizes earning your trust above all else.

Sincerely,

Jason Morris
Treasurer



Statement of Activities

	JUNE 30, 2022	JUNE 30, 2021
Revenue and Support		
Contributions	\$31,789,000	\$17,474,000
Special events revenue, net of direct expense	5,483,000	4,741,000
Bequests	313,000	3,998,000
Other Revenue	(2,308,000)	14,604,000
Total Revenue	\$35,277,000	\$40,817,000
Expenses		
Research	\$27,388,000	\$21,377,000
Public health education	2,699,000	1,683,000
Management	3,075,000	2,697,000
Fundraising	7,079,000	5,836,000
Total Expenses	\$40,241,000	\$31,593,000
Total Change in Net Assets	(\$4,964,000)	\$9,224,000
Issuance of common and preferred stock by Opus	4,459,000	0
Net assets as of June 30	164,589,000	165,094,000

Statement of Financial Position

	JUNE 30, 2022	JUNE 30, 2021
Assets		
Cash and investments	\$112,923,000	\$131,966,000
RD Fund investments	37,104,000	21,507,000
Pledges receivable, net	23,017,000	13,673,000
Other assets	1,275,000	3,844,000
Trusts and other funds	7,597,000	8,704,000
Fixed assets, net	813,000	949,000
Total Assets	\$182,729,000	\$180,643,000
Liabilities		
Accounts payable and accrued liabilities	\$2,108,000	\$2,937,000
Research grants payable	15,215,000	11,728,000
Deferred revenues	210,000	266,000
Liabilities under trusts and other funds	607,000	618,000
Total Liabilities	\$18,140,000	\$15,549,000
Net Assets	\$164,589,000	\$165,094,000
Total Liabilities and Net Assets	\$182,729,000	\$180,643,000

National Trustees

The Foundation's National Trustees are leadership-level volunteers who support the Foundation's fundraising, organizational development, and volunteer recruitment efforts.

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-

Strategic Council

The Strategic Council was created with the goal of connecting young professional leaders to drive the next wave of innovation at the Foundation Fighting Blindness from a unique and diverse vantage point, leveraging various backgrounds and talents. They work directly with the Foundation leadership and management to collaborate and problem-solve strategic challenges and opportunities being faced today—preparing themselves to be the next generation of leaders for the Foundation.

- | | | |
|-----------------------------------------------------------|-------------------------|-----------------------|
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*Elected to Board FY23



RD FUND

2022 Update

The RD Fund is a 501(c)(3) not-for-profit subsidiary of the Foundation Fighting Blindness that invests in cutting-edge companies focused on inherited retinal diseases. These investments further the research and generate even more funds that are poured right back into furthering our mission. The RD Fund portfolio companies leverage over five times the RD Fund's invested capital from outside traditional venture capital firms. To learn more about the RD Fund, visit: RDFund.org

A Letter from the Chair

When I think about what I want to convey to Foundation donors about the RD Fund, the first things that come to mind are an image of a construction site and a feeling of excitement. In my work with Gordon Gund over the years, we did a lot of planning and building. I see investing as being like the process of building. Human capital is the bricks, venture capital is the mortar, and when combined, you have something much stronger than either is by itself.

The Foundation has been producing bricks—human capital in the form of the science that our researchers ponder daily—for the past 50 years. In 2018, the RD Fund was launched with an initial investment of \$72 million, enabling us to fund ten promising companies. In my view, the venture capital from the RD Fund serves as the mortar that, when combined with all those bricks, can build some pretty amazing structures. I've served as the chair of the RD Fund since its creation and it's never stopped being exciting.

The RD Fund has an independent board of directors comprised of investors, executives, and clinicians—inquisitive minds from all across science and business. They all share a passion for bringing every possible resource to bear in the quest to end blinding retinal diseases. The RD Fund leverages the full weight of the Foundation's knowledge and resources, including the Scientific Advisory Board, the Clinical Consortium, and the My Retina Tracker Registry—along with an experienced and skilled management team.

Within a few short years, the RD Fund produced its first exit when Novartis

acquired Vedere Bio, netting a return of capital several times our initial investment. That success is a proof of concept for the RD Fund. It happened because of the Foundation's reputation as a leader in this space and because of the trust investors, companies and researchers place in the Foundation. The financial returns from this transaction and others will be put to work, making future research investments and RD Fund investments.

To seize this huge opportunity at the RD Fund, in the past year, our board has expanded by three members: Jean Bennett, MD, PhD, Catherine Bowes Rickman, PhD, and José-Alain Sahel, MD. Also, I am happy to share that after four years as chair, I will be passing the baton to fellow board member Adrienne Graves, PhD, who is uniquely positioned to take the RD Fund to its next stage. I look forward to staying on the board to help the RD Fund in the years ahead.

When I think about the current speed of scientific discovery in this field, I am reminded of an analogy of Lulie Gund's. She described the progress of the science and clinical trial opportunities like the sound popcorn kernels make when they are getting hot. The popping starts out slow, and it continues to build. You can trust that your gift to the Foundation is supercharged by the RD Fund and that the popcorn kernels will continue to pop faster and faster in the years ahead. Thank you for your trust and your investment.

With gratitude,

Warren Thaler
Chair, RD Fund



RD FUND

In its first four years, the RD Fund has invested in promising companies, including:



Atsena is developing gene therapy products, including a clinically staged candidate for one of the most common causes of blindness in children. —Pat Ritschel, MBA, CEO



CheckedUp is the only, physician-founded, specialty healthcare technology platform designed to engage patients, caregivers, and physicians in the waiting room, exam room, and at home. —Richard Awdeh, MD, CEO



Lookout Therapeutics is a RD Fund spin-out company founded by a leading venture capital group with significant expertise in gene therapy and rare diseases. —Paul B. Manning, CEO



Nacuity is developing an anti-oxidant treatment for retinitis pigmentosa and other related indications, including Usher syndrome. —Halden Conner, CEO



Nayan Therapeutics is developing variant-agnostic therapies to treat inherited retinal diseases such as forms of retinitis pigmentosa. —Milind Deshpande, PhD, CEO



Opus Genetics combines unparalleled insight and commitment to patient need with wholly owned programs in numerous orphan retinal diseases. —Ben Yerxa, PhD, CEO



ProQR is developing RNA therapies to treat inherited retinal diseases, including Leber congenital amaurosis and Usher syndrome. —Daniel de Boer, MBA, CEO



SalioGen Therapeutics is focused on developing therapies for more patients with inherited diseases that are beyond what is addressable with current technologies, initially focusing on inherited macular disorders and inherited lipid disorders. —Ray Tabibiazar, MD, CEO



SparingVision is developing a novel gene therapy approach for the treatment of inherited retinal diseases such as retinitis pigmentosa. —Stéphane Boissel, MBA, CEO



Stargazer Pharmaceuticals is an ophthalmic biotech company focused on developing a novel visual cycle modulator to slow the accumulation of toxic retinoids in the eye for Stargardt disease. —David Meek, CEO



Vedere Bio (I and II) is a biotech company utilizing novel ocular gene therapy technologies to develop a pipeline of vision restoration and vision preservation therapies for underserved indications. —Cyrus Mozayeni, MD, MBA, CEO



RD Fund Launches Opus Genetics to Advance Gene Therapies for Inherited Retinal Diseases

In September 2021, the RD Fund launched Opus Genetics, a patient-focused gene therapy company targeting inherited retinal diseases. Seed financing of \$19 million was led by the RD Fund with participation from the Manning Family Foundation and Bios Partners.

The company's lead programs are licensed from the University of Pennsylvania and will focus on treatments to address mutations in genes that cause different forms of Leber congenital amaurosis (LCA). Opus's lead program, OPGx-001, is designed to address mutations in the LCA5 gene, which encodes the lebercilin protein. LCA5 is one of the most severe forms of LCA, affecting approximately one in 1.7 million people. The company's second program, OPGx-002, will focus on restoring protein expression and halting functional deterioration in patients with retinal dystrophy caused by mutations in the RDH12 gene (LCA13), which affects one in 288,000 people. Recent preclinical

data have demonstrated the potential for both of these novel approaches to improve structure and function. Opus expects to file an IND for its OPGx-001 program at the end of 2022 and enter a clinic trial early in 2023.

This is the first spin-out company internally conceived and launched by the RD Fund to further the Foundation's mission. The initial seed funding will enable Opus to advance the preclinical research of its scientific founders, Jean Bennett, MD, PhD, the F.M. Kirby Emeritus Professor of Ophthalmology at the Perelman School of Medicine at the University of Pennsylvania; Junwei Sun, chief administrator of Penn's Center for Advanced Retinal Ocular Therapeutics (CAROT); and Eric Pierce, MD, PhD, William F. Chatlos Professor of Ophthalmology at Harvard Medical School and Massachusetts Eye and Ear. Dr. Bennett and Mr. Sun are also members of the Spark Therapeutics founding team.

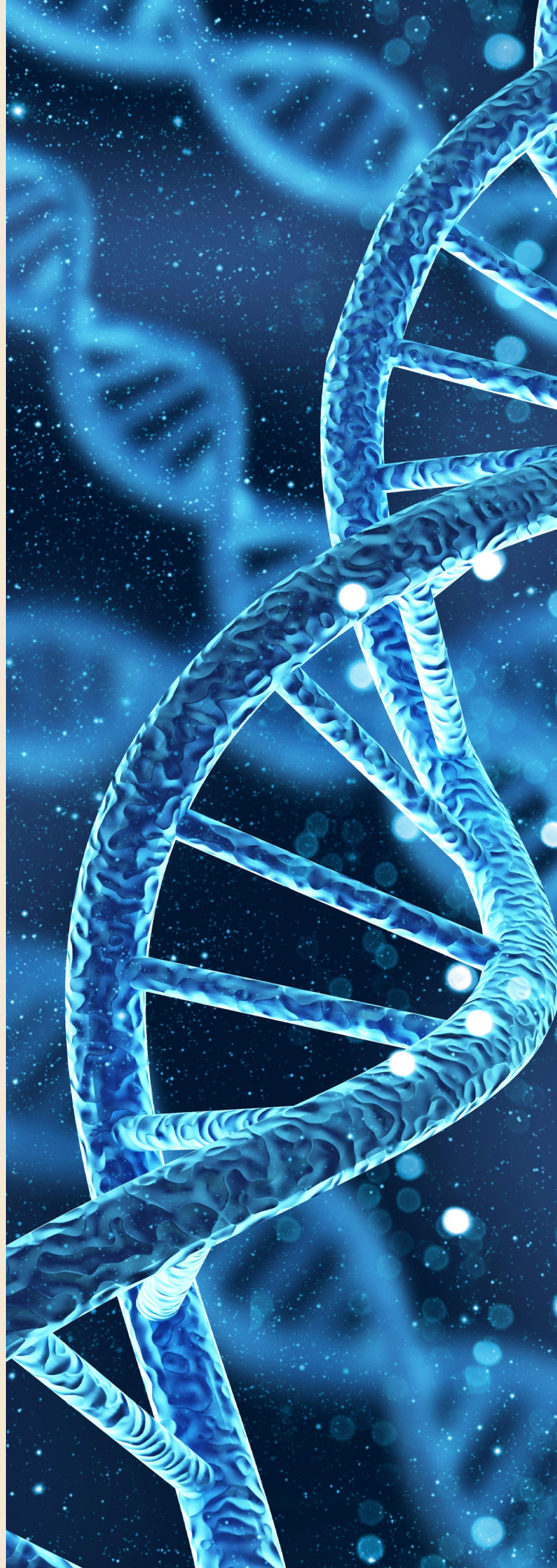
"I've dedicated my career to the research and development of treatments for blinding

diseases, and I'm eager to continue to build on this work with the RD Fund, an organization that understands the science and is deeply ingrained in the patient community," said Dr. Bennett. "Founding Opus enables us to progress our first two programs in Leber congenital amaurosis while building an engine to move additional treatments toward the patients who need them."

"Opus is a first-of-its-kind model for patient-focused therapeutic development. As the first company launched by the Foundation's venture arm RD Fund, Opus is uniquely positioned to bring experts, resources and patients together to efficiently advance ocular gene therapies for small groups of patients that to date have been neglected," said Ben Yerxa, PhD, CEO of Opus. "We're grateful for our fellow investors and supporters who share our commitment to realizing the promise of improving vision for people with devastating sight-limiting diseases, and look forward to building upon the pioneering work of Dr. Bennett, Mr. Sun and Dr. Pierce, and expanding our pipeline with more programs soon."

Dr. Yerxa co-founded and launched Opus with Peter Ginsberg, Rusty Kelley, PhD, and Jason Menzo, who also serve as the management team of the RD Fund. The Board for Opus is comprised of Drs. Yerxa, Kelley, Bennett and Graves.

"While potential treatments for these ultra-rare conditions have existed for years, families have been stuck in a holding pattern waiting on someone to deliver a feasible business model to bring them to market," said Paul Manning, Manning Family Foundation. "We're thrilled to be a part of the launch of Opus Genetics to establish a patient-first priority and build capabilities to tackle manufacturing obstacles and access to life-altering treatments for the people who need them most."



The RD Fund 1 Investment Financial Summary:

ASSETS	JUNE 30, 2021	JUNE 30, 2022
Funds Committed to Date	\$53,783,000	\$53,958,000
Reserves for future funding for RD Fund Portfolio companies	19,186,000	19,011,000
Funds for Future investments	-	-
Total Assets	\$72,969,000	\$72,969,000

The RD Fund 2 Investment Financial Summary:

ASSETS	JUNE 30, 2021	JUNE 30, 2022
Funds Committed to Date	\$10,000,000	\$12,000,000
Reserves for future funding for RD Fund Portfolio companies	20,000,000	8,000,000
Funds for Future investments	11,100,000	24,908,000
Total Assets	\$41,100,000	\$44,908,000

RD Fund Leadership and Management

Board of Directors

Warren Thaler, MBA
Chair, RD Fund

Adrienne Graves, PhD*
Chair, RD Fund

David Brint
Chair, Foundation Fighting Blindness

Anthony P. Adamis, MD

Jean Bennett, MD, PhD*

Catherine Bowes Rickman, PhD*

Eugene de Juan, MD

Jacque Duncan, MD

Kelly Lisbakken

José-Alain Sahel, MD*

Jonathan Steinberg, MD

Management Team

Rusty Kelley, PhD, MBA
Managing Director, RD Fund

Jason Menzo
Chief Executive Officer

Peter Ginsberg
Chief Operating Officer

Claire M. Gelfman, PhD
Chief Scientific Officer

*Elected to Board FY23

For Mark, *winning* means being there for his family.

Every day, Mark fights retinitis pigmentosa, a blinding retinal disease. But even while his vision is taken, his family gives him hope. Because whether he's helping run their business, or enjoying time at home with his wife and sons— ***Mark knows he's not fighting alone.***

For more than 50 years, the Foundation Fighting Blindness has been committed to finding treatments and cures for blinding retinal diseases. And our nationwide community of local chapters provides networking and support for people with vision loss, as well as their loved ones. Because the best way to fight against blinding diseases, is to fight together.



FOUNDATION **FIGHTING
BLINDNESS**
Together, we're winning.

FightingBlindness.org

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