

Together, we'll see an end to vision loss.

WINNING THE FIGHT



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

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As of December 31, 2021

To learn more about how you can help accelerate the quest for cures through the Victory for Vision campaign, contact Judy Taylor at jtaylor@fightingblindness.org.

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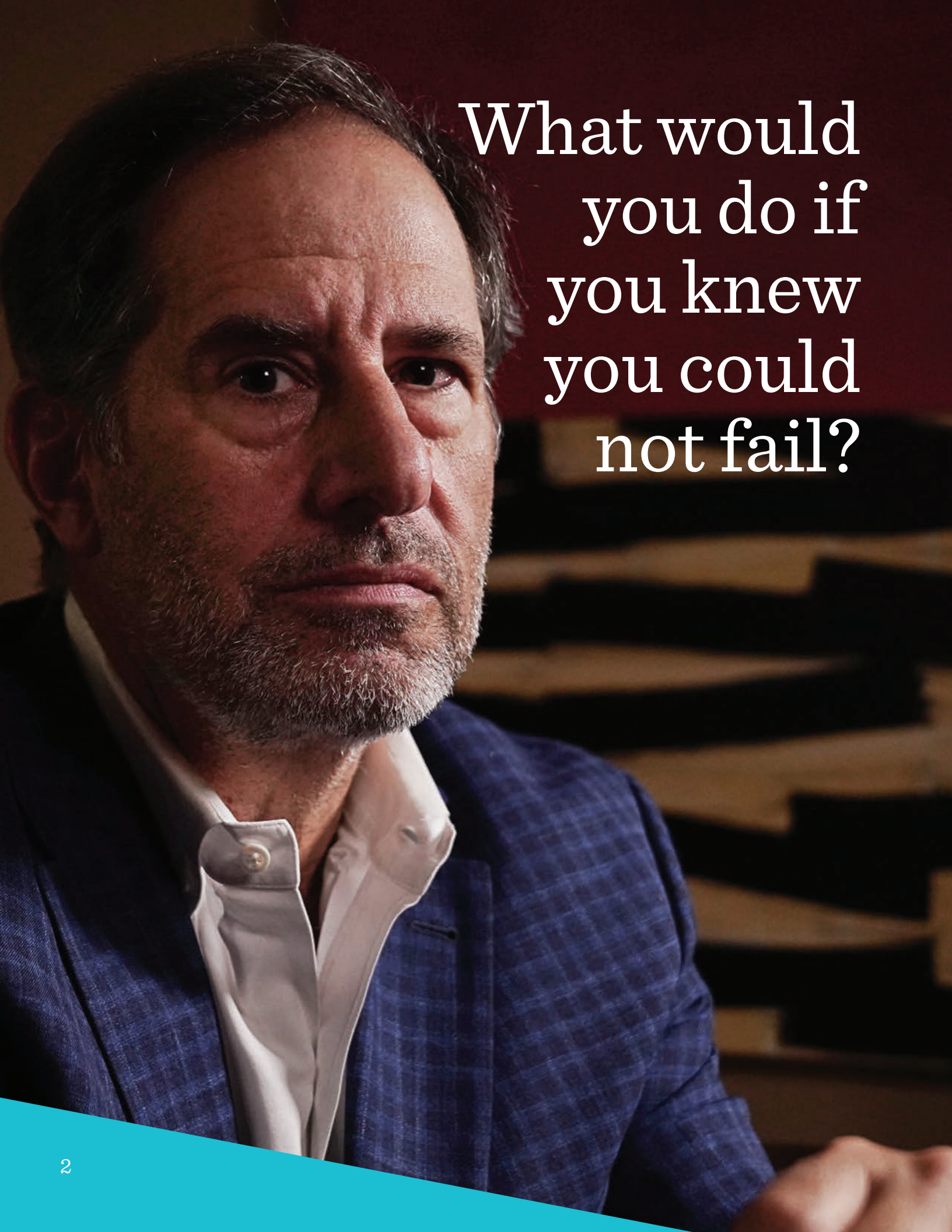
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Timeline of Triumphs Throughout

A close-up portrait of David Brint, a middle-aged man with a beard and mustache, wearing a blue blazer over a white shirt. He is looking slightly to the right with a serious expression.

What would you do if you knew you could not fail?

What would your answer be?

For me the answer is clear.

I would give my time, my money, and my leadership to help find a cure for the disease that has robbed my son of his sight.

I would fight for my son and for the millions of people affected by vision loss caused by blinding retinal diseases.

I would invest generously so the world's leading scientists could do what they do best—discovering treatments and cures.

I would celebrate the small vision victories because I've learned first hand that it's the small victories that add up to the big wins.

I would be relentless in asking others to join me, because this isn't a solitary journey. It's a journey that requires all of us.

And so that's what I'm doing. And that's what I'm asking you to do.

Pictured to the left:

David Brint

Victory for Vision Campaign
Co-chair and Board Chair,
Foundation Fighting Blindness

I have supported Foundation Fighting Blindness for more than 12 years because I wanted to be part of a winning team. I wanted to defeat the diseases that cause blindness. The Foundation's best-in-class team has been winning small victories in the fight against the diseases that cause blindness since 1971. With donors as partners, the Foundation works tirelessly to wipe out these diseases—one by one.

But I am only one of many in this fight. The Foundation Fighting Blindness community is international and inclusive. I've talked to countless mothers and fathers whose children started their lives with the knowledge that they will go blind, as well as seniors in their golden years who are going blind due to macular degeneration.

It's their stories, your stories and everyone's future that drive us.

We are on the precipice of curing blinding retinal diseases. No more parents being told their children will become blind. No more young adults being told they will go blind and no more seniors being told their final years will be in the dark. This is the time to be part of the winning team that will help millions of people.



1971: The Retinitis Pigmentosa Foundation is founded, which later would become the Foundation Fighting Blindness.
Pictured left: Gordon and Lulie Gund



1974: The first Foundation-funded research center is established at the Berman-Gund Laboratory at Harvard University.



1975: The first scientific workshop on retinal degenerative diseases is held.



1979: The Foundation funds five research centers.

Today’s outlook is bright, brighter than it has ever been. In fact, 20 years ago, I would have told you that I have no idea if we can cure this. Today I know it’s going to happen—we will cure these blinding diseases. It isn’t unreasonable to think that in my lifetime we will have found treatments or cures for most retinal diseases.

We have critical mass and we have the infrastructure in place. Now is the time to bring all the resources together to cure these diseases.

Together, we will win. We will finally defeat the diseases that cause blindness. We will have victory for vision.

I respectfully request that you join us in this fight against vision loss. We can’t let another generation go by without treatments and cures. **Will you join me?**

With my sincere thanks,

David Brint
Victory for Vision Campaign Co-chair and
Board Chair, Foundation Fighting Blindness



We are at a critical point in our history—50 years of fighting, 50 years of progress—with more cures on the horizon. As we approach our 50th anniversary year, we know we are nearing the finish line for so many of these diseases—but we aren’t there yet.

There are no medals for winning this fight—just treatments and cures. Together, we’re winning.

.....



1984: The Foundation funds 11 research centers.



A campaign to radically accelerate treatments and cures for the next generation.

The Victory for Vision goal: Invest an additional \$75 million in sight-saving research—research that is on the cusp of treatments and cures.

Your generous investment will be:

- significantly dedicated to a robust research pipeline
- in good company thanks to a generous \$5M leadership gift from the Manning family
- ultimately stretched even further by the Retinal Degeneration Fund, meaning bigger impact and better outcomes
- making a life-changing difference for millions of people who are losing sight due to blinding retinal diseases

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 preventions, treatments and cures.

We’ve come so far—but there’s so much left to do. For the first time in human history, vision loss is being treated and even cured. But these important breakthroughs would stop without research funded by the Foundation Fighting Blindness... without the research made possible by you.



1988: The first success of retinal cell transplantation in animals is achieved.



Diagnosed with Stargardt disease at the age of 15, Elizabeth Baker learned early that while she couldn't control her vision loss, she could control how she responded. "It was sink or swim, and I chose to swim." Now 45, she lives in Chattanooga with her husband and two children and competes with the USA Paratriathlon Team.

"I don't think of my vision loss or diagnosis as something that limits me," says Elizabeth. "It's a part of me and although having limited vision isn't the easiest, it's made me the strong person I am today and opened new doors to accomplish some pretty amazing things."



1989: The first retinitis pigmentosa (RP) gene is identified.

The Victory for Vision Campaign

Will you make a triple commitment so that the next generation will never know the effects of vision loss? There are three equally important ways to participate.

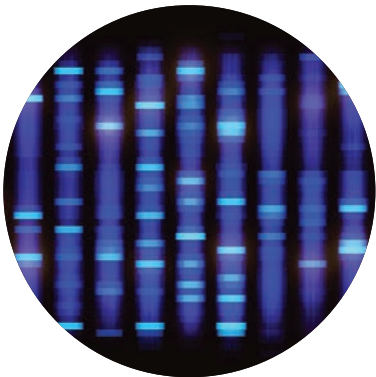
- 1) Transformational Investments:** A collective of givers making multiyear major investments ranging from \$25,000 to \$1,000,000+.
- 2) Legacy Investments:** A group of leaders leaving a personal legacy and securing sight-saving research for the next generation by designating the Foundation Fighting Blindness in their estates or wills.
- 3) Champion Investments:** A community of hundreds of thousands of donors and volunteers championing our mission on national and grassroot levels.



1993: Vitamin A is shown to slow vision loss in RP.



1995: The Retinitis Pigmentosa Foundation's name is changed to the Foundation Fighting Blindness.



1997: The first Stargardt disease gene (ABCA4) is identified.

Our 50 years of research is making a significant impact on the lives of people with inherited retinal diseases—and we aren't stopping now. Thanks to caring donors like you, we have made great progress toward finding cures, including the identification of more than 270 genes linked to retinal diseases. In fact, we have reversed blindness and restored vision through a breakthrough therapy.



1998: The Usher 2A gene is identified.



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



2000: An artificial retina is implanted in humans. Gene therapy restores vision in dogs with Leber congenital amaurosis (LCA).

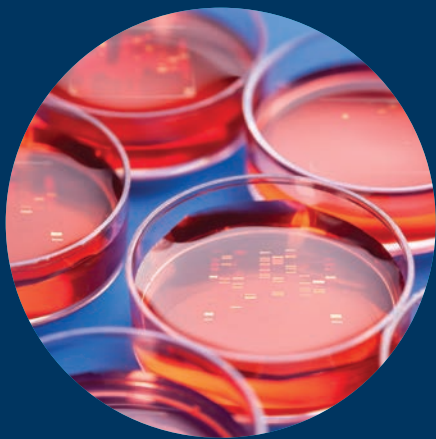
Alex is one of the many whose life has been changed thanks to the Foundation Fighting Blindness. If Alex had been born 50 years ago, before our quest for cures began, he would have been blind by his 12th birthday because there was no treatment for his disease. Today, thanks to research conducted by the Foundation Fighting Blindness, he was diagnosed and treated before he was six years old—before he was even old enough to understand the disease that threatened to take his sight.

Alex is just one of many who have benefited from a treatment discovered through research funded by the Foundation Fighting Blindness.

The Foundation has invested more than \$800 million in research and clinical trials. There are nearly 100 researchers around the world who spend their lives trying to learn more about how the eye works and find breakthroughs. And it's working.

Fifty years of tireless work is paying off. It would be a shame to stop now. With your help, we can achieve victory for vision.

Your financial commitment is ultimately stretched even further thanks to the Retinal Degeneration Fund's ability to attract additional investors and believers in the work. Best of all these funds go directly to programs that are ready for clinic or already in clinic.



2001: More than 100 genes are known to cause retinal degenerative diseases.

Because of donors like you, we've had victories—but beating each inherited retinal disease is now a matter of time and money.

“The Human Genome Project took ten years and \$3 billion to sequence the complete human genome.” says Foundation Fighting Blindness CEO Ben Yerxa.

“Now you can sequence the human genome in two weeks for \$10,000. Now anyone diagnosed in the US with an inherited retinal disease can be genetically tested at no cost through the Foundation's Open Access Program.

We have the tools to attack the problem. But the next problem is that we have approximately 300 genes. Each one is expensive to attack. There is no shortage of projects worthy of full funding, because we understand the biology. We just need to get on it.”

After a half century of research, treatments and cures are in our grasp. But we need funds to keep up with the science. That's how we achieve a victory for vision.



2002: Encapsulated Cell Technology (ECT) delivers CNTF (protein) to preserve vision in animals with RP.



2003: Phase I human clinical trial for ECT-CNTF therapy to treat RP begins.



2004: Researchers develop an Usher 1C animal model. The Foundation creates the National Neurovision Research Institute (NNRI).

“We cast a wide net to address the broad and diverse spectrum of diseases and forms of vision loss. Whatever it takes to address each person’s disease and vision needs. If we are to continue to accelerate the pipeline to vision, donors are essential.”

— Ben Yerxa, CEO
Foundation Fighting Blindness

The Pipeline to Vision

For the first time in human history, vision loss is being treated and even cured. Fundamental to this progress is a robust and accelerated Pipeline to Vision. Since 1971 we have fought to recruit a generation of researchers. Scientists whose life's work has been to drive this research are leading the way to



Jacque Duncan, MD
Professor of Clinical
Ophthalmology,
Beckman Vision Center,
University of California

preventions, treatments and vision restoration for the degenerative retinal diseases. Scientists like Dr. Jacque Duncan, a researcher at University of California, San Francisco, who also serves as the chair of the Foundation's Scientific Advisory Board.

“We are learning lessons all the time,” says Dr. Duncan. “Every day we’re discovering new genetic causes.”

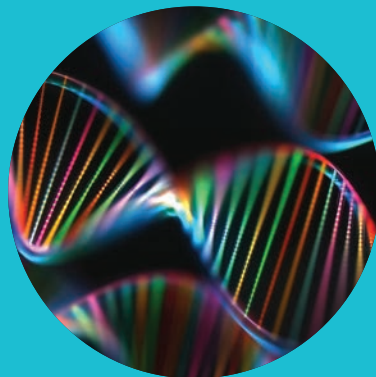
We’ve proven that it’s possible to defeat these diseases. With your help, we will move beyond possible to a true victory for vision.



2006: Researchers turn stem cells into retinal cells.



2006: Lucentis™ is approved by the FDA for wet AMD, halting vision loss in 90 percent of patients who are treated.



2006: Researchers use gene therapy to successfully treat Usher 1B in animal models.

Five Essential Components



1. Engagement: The Foundation has over 40 volunteer-led chapters across the U.S. These dedicated volunteers raise funds, increase public awareness and provide support to families affected by retinal diseases in their communities. Annual VisionWalk events are essential to bringing new friends and supporters.



2. Investment: Today, the Foundation is the world’s leading private funder of retinal disease research. It has raised more than \$800 million since its inception in 1971 in support of its efforts to reverse blindness and restore vision.



3. Research: Thanks to caring donors like you, we have made great progress toward finding cures, including the identification of approximately 300 genes linked to retinal disease. In 2020 we awarded more than 80 grants and funded over 90 investigators and 67 institutions around the world.



4. Treatments and Cures: We have reversed blindness and restored vision through a breakthrough therapy. It’s clear that our research over the last five decades can and will have a significant impact on the lives of people with inherited retinal diseases.



5. Victory: Today, thanks to generous donors like you, we’re winning the battle for vision. Winning means giving what it takes. It means defeating the diseases that cause blindness. Winning means victory.

With more than 40 clinical trials currently in process, it appears that now more than ever, curing the vast majority of blinding retinal diseases is simply a matter of time and money.

"Because of the tremendous progress made, thanks in part to Foundation funding, we are really on the cusp of restoring vision to lots and lots of people,"

—Michael Young PhD

Director, Minda de Gunzburg Center for Retinal Regeneration



2005: The CFH gene is implicated in 50 percent of age-related macular degeneration (AMD) cases.



With your help, we find the best people and do everything we can to ensure their success.

Meet Dr. Michael Young, director of the Minda de Gunzburg Center for Retinal Regeneration and an associate professor of ophthalmology at Harvard Medical School. Dr. Young has a lifelong love of science and research, but he is focused on work that is in line with the mission of the Foundation Fighting Blindness.

"My passion is to restore vision in the blind," he said. "My mother is almost completely blind from macular degeneration. She was a voracious reader and that is the thing she is missing the most."

He says the advances that have been made thanks to generous investments from donors are tremendous. "We are close to picking off these diseases one by one. That is new. Ten to 15 years ago there was no treatment for any inherited blindness."

Dr. Young has dedicated his career to changing that, and his mother's vision loss is one of his sources of inspiration.



2007: Phase 1 clinical trials of gene therapy for LCA begin. Phase 2 human clinical trial of DHA begins for X-linked RP.



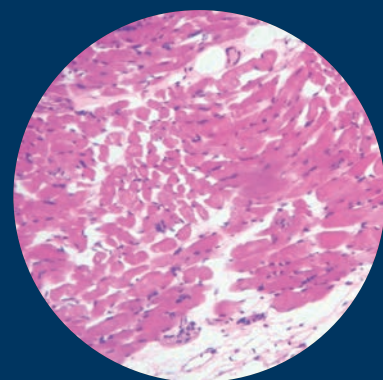
2008: More than 140 genes are linked to retinal degenerative diseases.



2008: The Foundation establishes a partnership with Genable to develop gene therapy for dominant RP.



2009: Twenty-five people who were nearly blind, experience some vision restoration in three Phase 1 clinical trials of gene therapy for LCA.



2010: Researchers use cell-based treatment to preserve vision in Usher 2A animal model.



2011: First patient treated in clinical trial of gene therapy for X-linked choroideremia.

Our mission is clear—drive the research that will provide preventions, treatments and cures for diseases that affect more than 50 million Americans and millions more throughout the world. Diseases like retinitis pigmentosa, age-related macular degeneration, Usher syndrome and the entire spectrum of retinal degenerative diseases are all within our reach—thanks to support from people like you.

We are on the cusp of vision-restoring treatments thanks to you.

At Schepens Eye Research Institute of Mass. Eye and Ear, Dr. Young studies the repair of the mature, diseased central nervous system. He is interested in the degeneration that occurs in the retina during disease or injury.

Dr. Young is currently studying human retinal stem cells with the goal of transplanting these cells to the diseased eye to establish functional connectivity between donor retinal stem cells and the mature, diseased host retina. His research focuses on gene and protein expression, substrate specific differentiation, and retinal transplantation in mice and pigs.

Dr. Young and his colleagues now aim to establish a novel stem cell therapy using retinal progenitor cells grafted to the mature, diseased host retina. This

approach will allow them to make important steps toward their goal of functional restoration of vision.

His work is behind the success of ReNeuron, a cellular therapy developer in the U.K. that has reported vision improvements in the treated eyes of several retinitis pigmentosa (RP) patients in the Phase 2 part of the Phase 1/2 clinical trial for its proprietary human retinal progenitor cells (hRPC).

The Foundation recently funded Dr. Young for preclinical and translational studies for the hRPC that helped make the ReNeuron trial possible. The hRPC are stem cells that have almost fully developed into photoreceptors, the retinal cells that make vision possible.

Clinical Trial Pipeline

Inherited Retinal Diseases and Dry AMD: 42 Trials (select)

Visit ClinicalTrials.gov for more details and trial contact information. This document is for informational purposes only. Information is subject to change, and its accuracy cannot be guaranteed.
Updated November 2020.

GENE THERAPIES..... PROGRESS

Achromatopsia (CNGB3) – AGTC	Phase 1/2
Achromatopsia (CNGB3) – MeiraGTx.....	Phase 1/2
Achromatopsia (CNGA3) – AGTC	Phase 1/2
Achromatopsia (CNGA3) – Tübingen Hosp	Phase 1/2
AMD (Dry) – Gyroscope	Phase 1/2
Choroideremia (REP1) – 4DMT	Phase 1/2
Choroideremia (REP1) – Nightstar	Phase 3
Choroideremia (REP1) – Spark	Phase 1/2
Choroideremia (REP1) – Tübingen Hosp	Phase 2
LCA (GUCY2D) – Atsena.....	Phase 1/2
LCA and RP (RPE65) – MeiraGTx.....	Phase 1/2
LCA and RP (RPE65) – Spark.....	FDA Approved
RP (PDE6B) – Horama.....	Phase 1/2
RP, Usher, others (optogenetic) – Allergan	Phase 1/2
RP, Usher, others (optogenetic) – Bionic Sight.....	Phase 1/2
RP, Usher, others (optogenetic) – GenSight	Phase 1/2
RP (RLBP1) – Novartis	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.....	Phase 1/2
X-linked RP (RPGR) – Nightstar	Phase 2/3

CELL-BASED THERAPIES..... PROGRESS

AMD-dry (RPE) – Astellas.....	Phase 1/2
AMD-dry (RPE) – Cell Cure.....	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, Usher (retinal progenitors) – ReNeuron	Phase 2
Stargardt (RPE) – Astellas	Phase 1/2

MOLECULES, PROTEINS, AONS..... PROGRESS

AMD-dry (C3 inhibitor) – Apellis	Phase 3
AMD-dry (CB inhibitor) – Ionis.....	Phase 2
AMD-dry (C5 inhibitor) – Iveric bio.....	Phase 2
LCA (CEP290, AON) – ProQR.....	Phase 2/3
LCA (CEP290, CRISPR) – Editas.....	Phase 1/2
RP (RHO, AON) – ProQR.....	Phase 1/2
Stargardt disease (emixustat) – Acucela.....	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 1
Stargardt disease (anti-RBP4) – Stargazer.....	Phase 2
Usher syndrome (NACA-anti-oxidant) – Nacuity	Phase 1/2
Usher syndrome 2A (AON) – ProQR.....	Phase 1/2



2011: ACT begins clinical trials of stem cell treatment for Stargardt disease and dry AMD.



2012: ACT stem-cell clinical trial reports two patients demonstrated improved vision.



2013: Since its inception, VisionWalk raises almost \$31 million to fund sight-saving research.

Bob and Lupe Reintsma
Legacy Donors



Leaving a Winning Legacy

Bob Reintsma has been passionate about finding cures for inherited retinal diseases for most of his life. Now, he and his wife, Lupe, want to make sure the work continues long after they're gone. And they're doing it in partnership with Foundation Fighting Blindness.

"It's something I've been affected with for more than 80 years," Bob said. "I can't think of a better place to leave whatever money one has left."

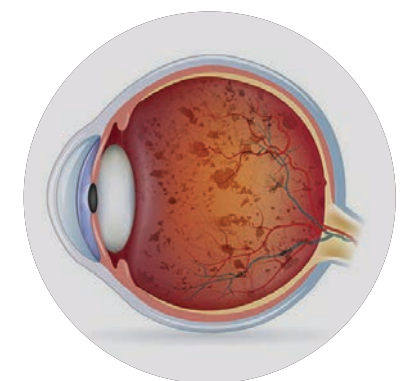
Born with X-linked retinitis pigmentosa, Bob's vision started to decline early in his life and by his mid-twenties, he was completely blind. Like many who have lost vision gradually over time, Bob tried not to let it affect his life as long as he could.



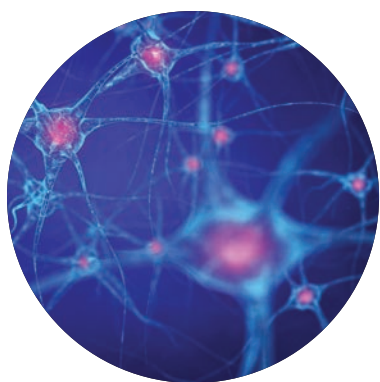
2014: The Foundation launches My Retina Tracker,® an online retinal-disease patient registry.



2015: Spark Therapeutics launches choroideremia gene therapy clinical trial.



2016: Approximately two dozen RP participants receive stem-cell therapy in jCyte clinical trial.



2016: First RP patient receives stem-cell therapy in ReNeuron.



2017: FDA approves LUXTRNA (RPE65) gene therapy—first FDA-approved gene therapy for the eye or an inherited condition.



2018: The Foundation invests up to \$7.5 million in ProQR's emerging therapy for USH2A.

But blindness didn't stop him. He learned to cope and remade himself as a real estate man—a successful one at that.

"When I got let go from regular work, I went down to the blind commission and took cane training and also went to real estate school to get my license," he says. "I worked in partnership with a driver and a reader. It worked out very well for quite a number of years."

It's a second marriage for both—Bob was divorced and Lupe was widowed. Bob still likes to talk about how they met.

"I'd heard about this dance and talked to a business partner about it. He took me, and I was seated at the same table as Lupe," he says with a smile. "I told her I would show her around the city. She was fairly new and didn't know Seattle that well, so I volunteered to be her guide dog."

Bob is quick to point out that it's actually Lupe who helps him get around.

"He was quite independent when we met," she says. "As we've gotten older, he's needed a little more help."

Over the years, they've kept tabs on the progress of researchers working to develop treatments and cures for inherited retinal diseases, particularly the work supported by

Foundation Fighting Blindness. As committed as they are to one another, they are equally committed to the mission of the Foundation. They are active in the Seattle chapter and its VisionWalks and have attended multiple VISIONS conferences.

"There's been so much progress made, since even the last 30 years," Lupe says, "that you know the money is being used wisely."

Bob and Lupe have committed significant planned gifts to the Foundation—and their generosity has inspired the creation of The Reintsma 2025 Legacy Society.

The goal of this new legacy society is to raise \$20 million as part of the *Victory for Vision* campaign. For Bob, lending his name to an effort that seeks to ensure the continued success of all this work is a fitting tribute to his friend, Foundation co-founder Gordon Gund.

"It's good that he started with the means and was interested in doing a thing like that," he says. "Somebody who, together with his doctors, took the reins and started the

Foundation. I certainly give my appreciation to him."

Both Bob and Lupe believe that the research taking place one day could eventually end inherited retinal diseases.

"It certainly looks like it to me," Lupe says, "from the things that we hear and read."

They both trust that a gift to the Foundation, whether outright or planned, is a worthwhile investment.

"I have to do it by trust," Bob says. "I don't have the money to do my own research so it has to be put in the hands of scientists and doctors and ophthalmologists. I can't think of a better place to put it."



Become part of a winning legacy

The Reintsma 2025 Legacy Society invites you to leave a legacy and provide future funding to defeat the diseases that cause blindness—to have victory for vision.

To help ensure tomorrow’s research pipeline is full we have claimed a bold goal of \$30M in legacy commitments by 2025. Commitments can be previously undocumented commitments, new commitments, and increased commitments, all with an opportunity to share the value in writing.

Legacy gifts include annuities, trusts, bequests, and other estate-planning vehicles.

To learn more about making a legacy gift and becoming a Founding Member of The Reintsma 2025 Legacy Society, contact John Corneille at jcorneille@fightingblindness.org or 952-314-7578.



2018: Nightstar’s choroideremia gene therapy moves into Phase 3 clinical trial.



2019: First Patient Receives ProQR’s Emerging LCA10 Therapy in Phase 2/3 Clinical Trial.



2020: AGTC Reports Positive Six-Month Results for XLRP Phase 1/2 Gene Therapy Trial.

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2021: Foundation Fighting Blindness launches *Victory for Vision* to ensure funding can keep pace with the science.

Today the battle for vision
isn't only won or lost
in the laboratory.
It's a battle for dollars
to make life-changing
work possible.
Will you join us?



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

VictoryForVision.org