LEGACY

SPRING 2021

A Publication for Supporters of the FOUNDATION FIGHTING BLINDNESS

Together, we're winning.

WHEN YOU LEAVE A LEGACY, THE NEXT GENERATION WINS.

Dear Friend,

As fellow supporters of Foundation Fighting Blindness, we thank you for your support. Because of you and other caring donors, the pipeline to vision is full like never before. It's producing treatments and cures. It's producing hope.

We're excited to announce a new opportunity to support the Foundation—it's The Reintsma 2025 Legacy Society. Inspired by the generosity of Bob and Lupe Reintsma, the goal of this new Legacy Society is to raise $20 million as part of the larger Victory for Vision campaign. Because we share Bob and Lupe's confidence in the Foundation's mission, we agreed to serve as co-chairs for this campaign, and we have each made a legacy commitment to become founding members of the Society.

This decision was easy as we each know what is at stake—both of us have inherited retinal disease and have family members suffering vision loss. As our eyesight has gotten progressively worse, our passion for helping find treatments and cures has only grown stronger. Today we are hopeful. Like you, we've seen the Foundation make tremendous progress in its mission. We now know what is possible.

We also know that the time is not far away when at least some of our family members will have sight restored. Because of the groundbreaking work funded by the Foundation, we are hopeful that when parents in the future get the devastating news that their child is losing his or her vision, there will be treatments and—hopefully—cures for them. But those treatments and cures will only become reality with the continued support of people like you.

Your support fills us with gratitude and hope.

With our thanks,

Davida Luehrs and Dan Day

Co-Chairs, Reintsma 2025 Legacy Society

Above left: Dan Day
Above right: Davida Luehrs and Chubb

WHAT'S INSIDE

WHY BOB AND LUPE REINTSMA ARE SUPPORTING FOUNDATION FIGHTING BLINDNESS

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. He learned to cope and remade himself as a real estate man—a successful one at that.

Bob says that today it is 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 the Foundation. 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." To help continue this progress, Bob and Lupe have committed significant planned gifts to the Foundation—and their generosity has inspired the creation of The Reintsma 2025 Legacy Society.

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 could eventually end inherited retinal diseases. They both trust that a gift to the Foundation, whether outright or as part of their legacy by way of an estate gift, 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."

From left to right: Bob and Lupe Reintsma in their Foundation Fighting Blindness VisionWalk t-shirts.

A BOLD GOAL TO SECURE $20 MILLION IN RESEARCH THROUGH LEGACY GIVING

A GOAL WITH LIFE-CHANGING IMPACT

In honor of the 50th anniversary of the Foundation, we are sharing a new opportunity to honor you, our most dedicated supporters, while also helping to secure tomorrow's life-changing research.

It's called the Reintsma 2025 Legacy Society, and it has a bold goal of $20 million in deferred gifts by 2025.

The Reintsma 2025 Legacy Society invites new members to leave a legacy, and it asks current legacy donors to confirm their commitment to the Foundation in writing so that we can better understand our future potential for research funding.

Why become a Founding Member? Founding members help lead the way for others to join them in helping secure the next generation of science. They also receive special recognition, insider research information, and exclusive mission insights.

Today, we can truly say that beating each inherited retinal disease is only a matter of time and money. As one of our most dedicated supporters, we invite you to learn more about the opportunity to leave a legacy that will help to ensure the research continues for the next generation.

ABOVE: John R. Corneille, J.D.
Director of Legacy Giving

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

Limited timeframe to become a Founding Member:
Now through Sept. 1, 2021

Co-Chairs, Reintsma 2025 Legacy Society
Dan Day *(Orlando, FL)*
Davida Luehrs *(Northern VA)*

Legacy Division Committee
Joel Davis *(Bethesda, MD)*
Martha Steele *(Boston, MA)*
Sherri Kroonenberg *(Littleton, CO)*

DID YOU KNOW?

If you are 70.5 or older and have a Traditional IRA, another option for charitable giving is the qualified charitable distribution, also known as a QCD. Donors may give as much as $100,000 directly from an IRA to a qualified charity like the Foundation Fighting Blindness. Required Minimum Distributions (RMD) also qualify for this tremendous giving opportunity. A qualified charitable distribution is not taxable income to the IRA account owner.

The Foundation Fighting Blindness appreciates your consideration of this giving option. We encourage you to consult a professional advisor to determine if this type of gift is right for you.

FOUNDATION INVESTS $5.5 MILLION IN SEVEN NEW TRANSLATIONAL RESEARCH PROJECTS

PROJECTS TARGET A VARIETY OF CONDITIONS, INCLUDING AGE-RELATED MACULAR DEGENERATION, STARGARDT DISEASE, RETINITIS PIGMENTOSA, AND USHER SYNDROME TYPE 3A

Through its Translational Research Acceleration Program (TRAP), the Foundation Fighting Blindness is funding seven new projects aimed at advancing potential therapies toward clinical trials.

To launch an authorized clinical trial, a therapy developer must submit an Investigational New Drug (IND) application to the US Food & Drug Administration (FDA)—a process that requires expensive preclinical studies, regulatory knowledge, and manufacturing expertise. TRAP-funded grants support these efforts and guide projects toward an IND submission.

"Our TRAP grantees are exceptional scientists developing therapies that have strong potential to reach the patients with retinal diseases who need them," says Chad Jackson, PhD, director of the Foundation's TRAP program. "Translational research is challenging and expensive, but our program gives these scientists critical resources to help them succeed."

Below: Scientist examines samples under a microscope.

SUMMARIES OF THE NEW TRAP GRANTS:

Dry AMD Gene Therapy

Bärbel Rohrer, PhD, Medical University of South Carolina, is conducting an animal study of a gene therapy designed to selectively deliver a component of complement factor H (CFH) to temper the overactive innate immune system in age-related macular degeneration (AMD). The approach is designed to mitigate retinal degeneration caused by the immune response, targeting the damage where it is most likely to occur.

Pharmaceutical for RP

Paul Yang, MD, PhD, is evaluating the drug mycophenolate as a therapy for multiple forms of RP and related conditions. Already approved by the FDA for inflammatory conditions, mycophenolate has been shown to reduce the accumulation of a molecule called cyclic guanosine monophosphate (cGMP). While cGMP is an important messenger molecule for converting light into electrical signals in the retina, too much of it is toxic and causes retinal degeneration.

Small-Molecule for Usher Syndrome 3A (USH3A)

Mahdi Farhan, MD, Usher 3 Initiative, is completing pre-IND toxicity studies to advance a novel small-molecule therapy for USH3A into a Phase 1 clinical trial. The emerging drug works by stabilizing the misfolded USH3A protein (clarin-1) and enabling it to better move to its target location in retinal cells, thereby striving to preserve structure and function.

Enabling the Retina to Generate New Photoreceptors

Tom Reh, PhD, University of Washington, is developing a process to enable the human retina to grow its own new photoreceptors. Thus far, he has used a small molecule to sprout photoreceptors from Muller glia in mice. The TRAP project is for evaluating the approach in a large animal.

Cross-Cutting Gene Therapy for RP

Stephen Tsang, MD, PhD, Columbia University, is developing a gene therapy to increase aerobic glycolysis—a process that generates energy—in cone photoreceptors of those affected by retinitis pigmentosa (RP). He believes the approach may preserve cones for RP patients and would do so independent of the mutated gene causing the disease.

RNA Therapies for Stargardt Disease

Rob Collin, PhD, Radboud University, is developing antisense oligonucleotides (AON)—tiny pieces of DNA—to mask splicing mutations in ABCA4, the affected gene in people with Stargardt disease. The AONs target mutations in RNA, the genetic messages used to build proteins that are necessary for a cell's health and proper functioning.

Restoring Dormant Retinal Cell Function

Hendrik Scholl, MD, Institute of Molecular and Clinical Ophthalmology Basel, is developing an optogenetic therapy to restore function to dormant cone photoreceptor cells for potentially a broad range of inherited retinal diseases. Cones are responsible for high-acuity, daytime vision, and in a certain percentage of patients, remain in a dormant state. This effort will perform late-stage preclinical studies that are required to start the first-in-human cone-based optogenetic vision restoration clinical trial. This optogenetic therapy produces a protein that makes dormant cone cells sensitive to light.

LEGACY
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FOUNDATION FIGHTING BLINDNESS
Together, we're winning.

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This and previous issues of **Legacy** are available online, where you can get the latest retinal research information, as well as updates on the Foundation's activities, on your PC and mobile devices.

For an online and accessible version of Legacy, visit **FightingBlindness.org/Legacy-Newsletter**

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LEAVE A LASTING IMPRESSION

Many people who don't have the resources to make a significant gift during their lifetime choose to leave a meaningful gift in their will. By leaving a gift to the Foundation, you will provide vital support for the research that will soon find an end to blinding retinal diseases. For more information on how you can leave a lasting legacy, visit: **FightingBlindness.org/Legacy-Giving**