LEGACY

FALL/WINTER 2021

A Publication for Supporters of the

FOUNDATION FIGHTING BLINDNESS

Together, we're winning.

Dear Friend of the Foundation,

With the end of another calendar year approaching, I find myself doing what we all tend to do—thinking back on the year that was and forward to the year that is to come. We've all done it enough times now that it can feel a little too familiar.

But of course, this year was unique in its own way—especially when it comes to the Foundation Fighting Blindness. Weathering a second year of pandemic life is enough to qualify as unique, but it was more than that. This year marks the Foundation's 50th anniversary. We hired a new chief scientific officer. And the science we fund is now developing at a breathtaking pace.

Which is why funding the important work of this Foundation is more crucial than ever. Half a century of research has begun to yield treatments and actual cures for inherited retinal diseases like the one that left me vision impaired. There is hope on the horizon but the fight to wipe out these blinding diseases is far from over. And legacy giving is one of the most effective ways to make sure the resources are always there to treat and cure more individuals.

In this newsletter, you will be introduced to the founding members of The Reintsma 2025 Legacy Society, a special giving initiative born from our Victory for Vision campaign. You'll also meet Dr. Claire Gelfman, PhD, who joined the Foundation earlier this year as chief scientific officer. Dr. Gelfman has experience in every step along the pipeline that leads from research to cures and is passionate about the quest for treatments and cures and equally passionate about explaining how it all works to supporters like you.

She also understands how important giving—especially legacy giving—is to the work that she and researchers across the globe do every day. Legacy giving is something anyone who believes in the mission of the Foundation needs to consider.

If you're already a member of The Reintsma 2025 Legacy Society, THANK YOU! If an inherited retinal disease affects you or a loved one, you're the reason we do this.
If you're considering joining the Society by making a legacy gift, I want to share this with you. I am 62 and have two adult children. They are my family, and I have provided for them in my end-of-life planning. But I also see the Foundation as part of my family and have made a legacy commitment accordingly. What greater gift could you make than by helping ensure the Foundation is here for future generations with a legacy commitment?

It goes without saying but is worth repeating—we all need to think beyond ourselves. And let's not forget Bob and Lupe Reintsma, the namesakes of our exciting new giving society. I think of Bob's words often— "I can't think of any better place to put my money."

Thank you, Bob and Lupe. And thank you for your continued support of the Foundation Fighting Blindness.

Sincerely,
John R. Corneille, J.D.
Director, Legacy Giving

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

WHAT'S INSIDE

NEW CSO UNDERSTANDS THE POWER OF SCIENCE—AND GIVING BACK

Dr. Claire Gelfman, PhD, credits her parents for her inquisitive mind and love of learning. She dedicated her doctoral dissertation to her mom, an English professor, and her dad, a doctor focused on allergy and immunology. So it's no surprise that she would jump at the chance to become chief scientific officer for the Foundation Fighting Blindness. But she was attracted to more than the thrill of cutting-edge science when she took the job.

"Everything I've learned has prepared me for this," she says. "Coming to the non-profit side is a way for me to give back. And I'm eternally grateful to donors who become part of the Legacy Society. It's a remarkable way to give back and support this mission."

On the job since April 2021, Claire is responsible for leading the overarching scientific strategy for the organization with a focus on research initiatives designed to accelerate new treatments and cures for inherited retinal diseases.

Claire says she's humbled to be working for an organization celebrating its 50th anniversary at a time when decades of hard work in the field are starting to pay off. But she's also aware that the work is far from done.

"The fact that we've been around and relevant for 50 years is amazing," Claire said. "I am hopeful we are about to see a lot of treatments and cures. But these are very complex diseases. There is a lot of great science underway right now that needs to be funded."

Which is why, she says, a program like The Reintsma 2025 Legacy Society is so important.

"I met a legacy donor recently whose child is affected," Claire said. "I looked at him in awe. It's the most selfless thing you can do, and leaving a legacy gift is what we need to keep all this going. All gifts to the Foundation, legacy and otherwise, are put to such good use."

Beyond her role of staying on top of the science and research that is the heart of the Foundation, Claire is attracted to the prospect of teaching people about the Foundation's work.

"I am deeply committed to helping our constituents understand the science and the impact of their donations and investments," she says. "Our donors and volunteers drive our mission, and it is essential they understand how their investments are making a difference."

She's confident that more understanding will lead to more investments—and ultimately more treatments and cures for inherited retinal diseases.

"I look forward to leveraging my preclinical and clinical development experience in the retinal gene therapy industry to help guide the Foundation's research efforts to get more therapies into the pipeline, across the finish line, and out to the people who need them."

ABOVE: Claire M. Gelfman, PhD
Chief Scientific Officer

INTRODUCING THE REINTSMA 2025 LEGACY SOCIETY FOUNDING MEMBERS

As co-chairs of the **Reintsma 2025 Legacy Society**, we are pleased to introduce an early list of founding members. We are grateful to these donors for caring about the Foundation's future in such a generous and thoughtful way, and we are proud to welcome each and every one to this important family of legacy donors.

These donors are among a special group of individuals who are helping to ensure that the Foundation can continue its research for future generations by remembering the Foundation in their legacy plans today. The Reintsma 2025 Legacy Society is named for Bob and Lupe Reintsma, who have made a significant impact on the mission of the Foundation by giving generously today and also establishing planned gifts that will benefit the Foundation beyond their lifetimes.

You, too, can be a founding member of the Reintsma 2025 Legacy Society. By doing so, you are helping to ensure that an amazing track record of success continues.

We believe in the Foundation's mission, and we want to do everything we can to support it. For both of us, the decision to include Foundation Fighting Blindness in our wills came down not to the question "Why should we do it?" but instead, *"Why wouldn't we?"* It is our hope that you feel the same way.

With gratitude,

Davida Luehrs and Dan Day
Co-Chairs, Reintsma 2025 Legacy Society

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

ABOVE: The Reintsma 2025 Legacy Society Badge

The Reintsma 2025 Legacy Society Founding Members

(as of October 1, 2021)

In Memory of Joshua Andrew Skeen, II
David Patrick Nixon
Dan Day
Doris Day
John R. Corneille
Julie A. Anderson
Sheila M. DuPerow
James W. Kenst
Martha Steele
Gertrude S. Field
Barbara R. Sokolsky
Leslie Held and James Chucker
Helen Davis
Joel and Elizabeth Davis
Bob Morgenstern
Susan and Art Weeden
Anne Vannice
Mr. and Mrs. Jim Luehrs
Thomas S. and Sharon May Wallsten
Richard and Elizabeth Kamis
Jeffrey and Susan Freed
Steve Hamby
Adam L. Verchinsky
Basil and Karen Petrou
Eduardo A. and Sylvia Velasquez
Friends of the Foundation — Anonymous

CHARITABLE GIFT ANNUITIES ARE A WAY FOR DONORS TO RECEIVE INCOME DURING THEIR LIFE AND HELP CURE BLINDNESS

A charitable gift annuity is a contract between a donor and a charity. The donor makes a gift of a certain amount and in return for the gift, the charity makes fixed payments to the donor during the donor's lifetime at predetermined interest rates. In addition, as a donor, a portion of the payments you receive from the annuity are tax free, and, depending on your particular tax situation, a current tax deduction may be available to you in the year in which you purchase the charitable gift annuity. See below and contact the Foundation or your tax advisor for more information.

Age	Annual Payment	Interest Rate
65	$420.00	4.2%
75	$540.00	5.4%
85	$760.00	7.6%

This example assumes a $10,000 gift. The annual payments shown are based on a onetime $10,000 charitable gift annuity.

RD FUND LAUNCHES OPUS GENETICS TO ADVANCE GENE THERAPIES FOR INHERITED RETINAL DISEASES

FIRST TWO PROGRAMS ARE FOR LEBER CONGENITAL AMAUROSIS: LCA5-LEBERCILLIN AND LCA13-RDH12

The Retinal Degeneration Fund (RD Fund), the venture philanthropy arm of the Foundation Fighting Blindness, has 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 restore structure and function. Opus expects to file an

Below: Researcher at work filling test tubes in laboratory.

IND for its OPGx-001 program in early 2022 and enter a clinical trial in mid-2022.

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."

"I am honored to support the Foundation's Reintsma Legacy Society as a lasting tribute to my brother, Joshua Andrew, who totally lost sight in one eye at an early age. Though he sadly died from cancer at age 59, the precious value of sight was always foremost in his heart and mind, and he would be proud of the Foundation's legacy of fighting to bring hope to those with vision loss."

— Karen Skeen,
Donor and Supporter

"I decided to include the Foundation in my estate plans so that if the time ever comes when my grandchildren, or anyone else's, experience vision loss, the scientists will have figured out how to help them."

—Anne Vannice,
Donor and Supporter

APELLIS TO SEEK FDA APPROVAL OF ITS DRY AMD DRUG

The biopharmaceutical company 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 (AMD). Monthly and every-other-month treatment with APL-2 reduced GA lesion growth by 17 percent and 14 percent, respectively, in the two trials. Treatments with the drug are made by injections into the vitreous, the soft gel in the middle of the eye. A total of 1,258 people were enrolled in the studies.

The company plans to submit a New Drug Application (NDA) for APL-2 to the U.S. Food and Drug Administration (FDA) in the first half of 2022. If approved by the FDA, the drug would be the first treatment available for GA.

While the OAKS trial met its primary endpoint of GA lesion growth, the DERBY trial did not. In the OAKS trial, monthly and every-other-month treatment with APL-2 reduced GA lesion growth by 22% and 16%, respectively, compared to sham (placebo) at 12 months. In the DERBY trial, APL-2 reduced lesion growth by 12% and 11% with monthly and every-other-month treatment, respectively, compared to sham at 12 months. APL-2 is designed to slow the progression of GA by inhibiting C3, a protein in the complement system. While complement is part of the human immune system that wards off harmful bacteria and viruses, it can cause damage if not controlled properly. Researchers have strong evidence that an overactive complement system is involved in the death of retinal cells in AMD.

According to Apellis, 1 million people in the United States have GA, a progressive condition that causes central vision loss due to loss of cells. There are currently no FDA-approved treatments for GA.

LEGACY
is published by:

FOUNDATION FIGHTING BLINDNESS
Together, we're winning.

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LEGACY

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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"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 than Foundation Fighting Blindness."

— Bob Reintsma,
Donor and Supporter