

LEGACY

SPRING/SUMMER 2022

A Publication for
Supporters of the

FOUNDATION
**FIGHTING
BLINDNESS**

Together, we're winning.

Dear Friends,

Spend any time with someone associated with the Foundation, and you're bound to learn something—from genetics to the miraculous functions of the eye to the detailed processes of clinical trials. The Foundation is the largest funder of retinal disease research in the world, and we are one of the preeminent drivers of educating on these diseases. Knowledge is power.

I hope you will take a few minutes to read this issue, which is full of informative articles about the science and ways you can support the science and secure your family's future. More than two years of living with COVID-19 has caused many of us to seriously consider our own mortality. Americans during the last couple of years have thought about, created, or reviewed their personal end-of-life plans in numbers never seen before. In light of this statistic, I'll step into my teacher role for a moment and address the basics of legacy giving.

What is an "estate plan?"

In its simplest terms, your "estate" consists of anything of value you own at the time of your death. An estate "plan" is what you decide, during your life, to do with those things of value at death. If you do not make the effort to create a plan before you die, then the state where you live at death will dictate where your possessions will go. No matter how much you love your state, I doubt you want it to make those kinds of decisions for you.

Directing where your hard-earned assets go at death can be done in a number of different ways, the most common being a will or trust. Assets can also be transferred by designating a beneficiary through life insurance policies, retirement accounts, investment accounts, and even basic checking and savings accounts. Many states also have provisions for transferring interests in real estate through a process very similar to a beneficiary designation.

A will or trust usually involves meeting with an attorney, although online will and trust options are becoming more popular. Creating or changing a beneficiary on an account can most often be done through the mail, e-mail, or other online methods.

Elsewhere in this edition, you can read about the Reinstma 2025 Legacy Society and its goal of identifying at least \$30 million in legacy commitments—funds that will be used to continue the crucial research the Foundation has been investing in for the last fifty years. You'll also learn about a new initiative to educate donors like you about the nuts and bolts of legacy investing and how important it is to causes like Foundation Fighting Blindness, established by long-time supporter Karen Petrou to honor her late husband, Basil.

You already believe in the mission of the Foundation, and I can't stress enough how grateful the Foundation is for that support—it helped get us as close as we have ever been to finding multiple treatments for inherited retinal diseases. Your continued support is critical to our mission, and creating a legacy gift—in whatever form or amount—will help ensure that one day no one will have to live with a blinding inherited retinal disease.

If you have questions about how best to provide for the Foundation as you plan for your future, please do not hesitate to contact me at (952) 314-7578 or JCorneille@FightingBlindness.org.

Sincerely,

John R. Corneille, J.D.



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

WHAT'S INSIDE ▾

Pg. 2 | The Karen and Basil Petrou Legacy Education Initiative

Pg. 3 | The Reinstma 2025 Legacy Society Founding Members

Pg. 4 | Chapter Event's Quest for Cures Also Seeks to Share the Power of Legacy Giving

Pg. 5 | Foundation Summit Highlights Robust Growth in Commercial Development for Retinal Disease Therapies

THE KAREN AND BASIL PETROU LEGACY EDUCATION INITIATIVE—SHINING A LIGHT ON HOW TO PLAN FOR TOMORROW

Karen Petrou understands the realities of end-of-life planning as well as anyone. She and her husband Basil have spent their careers in the financial services industry, and when Basil died in 2021 after a long, heroic battle with pancreatic cancer, it was a comfort for her that his affairs were in good order. Still, the experience left her with a realization of how daunting the financial and legal implications of losing a spouse can be.

“When Basil died, all of the impacts of estate planning became a reality for me,” Karen said. “It was a real reminder of how important it is.”

She realized how easy it would be for the experience to be totally overwhelming, even for people who were prepared. That realization inspired Karen to help create the Basil and Karen Petrou Legacy Education Initiative.

The Basil and Karen Petrou Education Initiative is born of the Foundation’s commitment to helping individuals ensure their estates do the best they can for their loved ones and the causes they care about. Debuting this year, the program will offer ongoing resources to help individuals and families explore and learn about end-of-life plans and strategies.

Karen is co-founder and managing partner of Federal Financial Analytics, Inc. She was diagnosed with retinitis pigmentosa when she was 18. Like many people experiencing progressive vision loss, early on, she said she was coping the best she could and trying to hide her vision issues. In the early 2000s, a friend introduced her to the Foundation.

“Basil and I found it really impressive,” Karen said. “We attended some VISIONS conferences and trustee meetings. The fact that my IRD was becoming more of a problem made it all the more interesting to us. Retinal diseases are often degenerative, and mine was clearly getting worse. Quite simply, we wanted treatments and cures, and to this day, I’m convinced that the Foundation is the best way to advance those as they come along.”

Karen has been on the board since 2006, and Basil was a Foundation Trustee. She says the Foundation’s disciplined approach to research has done two unique things. First, there is an astute

team of expert science advisors directing all investments. And second, they are leaders in innovative ways to fund biomedical research. The Retinal Degeneration Fund (RD Fund), the Foundation’s venture philanthropy arm, is a perfect example.

“The RD Fund is amazing,” Karen said. “I have some experience in this, and no one has done it the way the Foundation has done it. They are exploring the frontier of exciting new ways to fund this research.”

Debuting this year, the Basil and Karen Petrou Education Initiative will come to life through dynamic content and stories across all the Foundation’s platforms—from seminars and conferences at VISIONS to webinars and other online resources.

Karen said she hopes that she and Basil’s belief in the Foundation will inspire others to support the work and possibly leave their own legacy.

“As long as the Foundation exists, we need to continue funding all the work that they’re doing,” she said. “There’s a lot of work to do. And I know that the funds raised through the Foundation’s various development channels are not going to fancy fundraising dinners. They are going to science.”

Visit www.FightingBlindness.org/PetrouLegacy for a full listing of events and opportunities, as well as helpful articles and online resources.



ABOVE: Karen and Basil as Basil is accepting an award at the Foundation’s 2019 DC Dinner.

THE REINTSMA 2025 LEGACY SOCIETY FOUNDING MEMBERS



A little more than a year after its creation, the **Reintsma 2025 Legacy Society** is surpassing all expectations. As Legacy co-chairs, we are excited to share with you that membership in the society has nearly doubled since the initial roster of founding members was introduced last fall. (You can see a list of all members on this page.)

Like these individuals, we believe in the Foundation's mission, and we want to do everything we can to support it. We are both affected by inherited retinal diseases, and we want to help others who might be treated or even cured, thanks to research funded by the Foundation. Legacy gifts are a critical part of making sure that those successes continue to happen.

Your written deferred commitment, of any value, demonstrates your belief that the Foundation Fighting Blindness is a leader in innovative retinal disease research. You can become a member through many legacy giving options, such as wills, charitable gift annuities, trusts, life insurance, or retirement plans. Your attorney or financial advisor may have suggestions that are best suited to your unique needs.

It's an honor and privilege to be part of a winning team and to know that our combined efforts could mean the end of these diseases forever. We hope that you agree and that you will join us.

With gratitude,

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

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 annually and by establishing legacy gifts that will benefit the Foundation beyond their lifetimes. It's 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. We are grateful for these generous supporters.

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 April 26, 2022)

Julie A. Anderson
Steven C. and Ruth Ferris Armstrong
Shari Arribere
Yvonne Chester Charitable Fund
Leslie Held and James Chucker
A.E. Colver, Jr. In Memory of Wife, Joni Lynn
John R. Corneille
Helen Davis
Joel and Elizabeth Davis
Doris Day
Dan Day
Sheila M. DuPerow
Gertrude S. Field
Jeffrey and Susan Freed
Deborah Garcia
Debra Glasper
Steve Hamby
Richard and Elizabeth Kamis
James W. Kenst
Boris and Saithong Lifshutz
Jason and Jole Lovelace
Janet Wyzansli Lowenthal
Mr. and Mrs. Jim Luehrs
Bob Morgenstern
David Patrick Nixon
Basil and Karen Petrou
Don and Nita Reed
Lori Rice and David Couzens
In Memory of Joshua Andrew Skeen, II
Martha Steele
Anne Vannice
Eduardo A. and Sylvia Velasquez
Adam L. Verchinsky
Thomas S. and Sharon May Wallsten
Susan and Art Weeden
Friends of the Foundation – Anonymous

CHAPTER EVENT'S QUEST FOR CURES ALSO SEEKS TO SHARE THE POWER OF LEGACY GIVING

For more than two decades, the Scramble for Sight has been raising funds to support the quest to wipe out inherited retinal diseases. This year's event, organized by the Foundation's Colorado Chapter, seeks to raise not just dollars but also awareness of the importance of legacy giving when it comes to supporting the Foundation Fighting Blindness.

This year's Microsoft Scramble for Sight presented by RE/MAX is set for July 18 at Sanctuary Golf Course in Sedalia, CO, south of Denver. Co-chair and co-founder Sherri Kroonenberg says that golf is just the beginning when it comes to this event. As an active volunteer for the Foundation's Legacy Division, she wants to make sure attendees come away knowing how important legacy giving is to the long-term success of the Foundation's research efforts.

"It's a golf event on the surface," Sherri said, "but everyone is there because of the Foundation. And this year's program will be special and will focus on the words and stories of five people reflecting multiple generations and multiple diagnoses, from Usher, LCA, PRPF8 to X-linked RP."

Speakers on the panel will range from baby boomers back to nine-year-old Olivia from Boulder, who was diagnosed with LCA at age five but was successfully treated with LUXTURNA® and now sees the world with "new eyes." Sherri says Olivia is living proof of how far Foundation-funded research in this space has come.

"Fifty years of hard work has paid off," Sherri said. "This child sees! Olivia reads with her eyes!"

For others on the program, treatments and cures are still just a hope for the future. Austin Burt, son of Scott Burt, co-chair of the event and Board Member for the Foundation, has yet to have the gene that causes his vision loss identified.

Sherri says she will host the panel discussion along with a representative from the title sponsor Microsoft. In addition to focusing on successes like Olivia's and ongoing searches for people like Austin, Sherri says she wants attendees to realize the power legacy gifts can have in the ongoing journey toward treatments and cures.

"We want people to see the generational impact," she says. "We want people to walk away knowing the importance of investing - the need now and the need long term."

Sherri's connection to the Foundation is her husband Carl, who was diagnosed with Usher syndrome in 1989. Usher syndrome affects both vision and hearing, and Carl

was wearing hearing aids when they met and lived with declining vision for years before he was finally properly diagnosed. She wrote to the Foundation, then known as the National Retinitis Pigmentosa Foundation, when she learned about it.

"They were the only ones that provided literature," Sherri says. "Suddenly, we weren't alone."

In 2000, Sherri and Scott came together and were asked by the Foundation to plan the event that would become Scramble for Sight. The Colorado Chapter was reignited along with the launch of the annual VisionWalk.

Involvement in the Foundation has inspired Carl and Sherri to live boldly despite his vision loss—they're avid tandem mountain bikers and runners, and they've hiked and summited Mt. Kilimanjaro.

"We decided we didn't want to be hindered," Sherri said. "And we haven't stopped."

In July, Sherri's adventure will be trying to top the \$285,000 the Scramble raised last year—along with helping people understand the power of a legacy gift to the Foundation.

"We never thought anyone would get anywhere near treating Usher syndrome because it's so rare," Sherri said. "But now there's a clinical trial. We are so encouraged by that. Leaving a legacy gift through the Foundation, we know that it ensures that the work that's been going on for 50 years will be accelerated going forward. And that's what gives us hope."

*While Scramble for Sight golf spots are sold out, one Platinum sponsorship is available, and there may be room for you at the dinner and program. Please visit, **ScrambleForSight.org** to learn more.*



ABOVE: Carl and Sherri mountain biking.

FOUNDATION SUMMIT HIGHLIGHTS ROBUST GROWTH IN COMMERCIAL DEVELOPMENT FOR RETINAL DISEASE THERAPIES

The Foundation's Investing in Cures Summit (ICS), held on April 2, 2022, in Half Moon Bay, California, convened 175 researchers, industry executives, and constituents to present and discuss the expanding and accelerating commercial development of emerging therapies for retinal degenerative diseases.

The event featured panel presentations on a broad range of modalities including -- gene- and mutation-specific therapies, cell-based treatments, and mutation-agnostic neuroprotective and optogenetic approaches – as well as perspectives on the research and investment climates.

Approximately 24 emerging therapies were discussed during the Summit. Listed below are a few of the research highlights.

John Flannery, PhD, a Foundation-funded professor at UC Berkeley, co-founder of Vedere Biosciences, and member of the Foundation's scientific advisory board, reviewed two optogenetic approaches he's developed that have been part of Vedere Bio's pipeline. (Vedere is a company in the Foundation's RD Fund portfolio.) Its original optogenetic therapy expresses a medium-wave green cone opsin that is thought to be more responsive to natural light than other optogenetic alternatives. In late 2020, Novartis acquired Vedere and that original cone opsin-based therapy. Subsequently, Vedere II, a new company, was launched to advance an optogenetic therapy that combines an opsin-like protein with a chemical photoswitch to potentially provide an even better response, one that can be modulated, in natural light.

Kapil Bharti, PhD, a senior investigator at the National Eye Institute, described his Phase 1/2 clinical trial for retinal pigment epithelial (RPE) cells derived from induced pluripotent stem cells (iPSC), which are transplanted on a biodegradable scaffold to enhance survival and facilitate proper RPE orientation. The emerging treatment is for people with GA. The iPSC are produced by taking a small sample of blood from the patient, turning back the clock on the cells so they revert to a stem cell-like state, and then coaxing them forward to become RPE. In the future, he plans to

develop patches that include photoreceptors and the choroid, the outer layer of vasculature that provides oxygen and nutrients to the retina.

Lukas Scheibler, PhD, chief innovation officer at Apellis, reported on his company's two Phase 3 trials for pegcetacoplan, a molecule that targets the C3 protein in the complement system, a part of the innate immune system which is overactive and damaging in people with AMD. The company is applying for FDA approval for pegcetacoplan for GA. In its OAKS trial, monthly injections of the treatment reduced GA lesion growth by 22 percent at 18 months. In its DERBY trial, monthly injections reduced lesion growth by 13 percent at 18 months.

Mark Shearman, PhD, executive vice president and chief scientific officer at Editas Medicine, discussed the company's CRISPR/Cas9 gene-editing therapy for LCA10 (common CEP290 mutation), which was the first of its kind to be administered to the human body. CRISPR/Cas9 works like a pair of molecular scissors to cut out the mutation in the gene. Editas' emerging treatment improved vision for the first two of three patients in a Phase 1/2 clinical trial. Editas is also in preclinical development for CRISPR/Cas9 treatments targeting USH2A (exon 13) and autosomal dominant RP (RHO).

Gerard Caelles, chief business officer, SpliceBio, discussed the company's emerging technique called protein splicing for overcoming the capacity limitations of typical adeno-associated viral (AAV) gene delivery systems. In protein splicing gene delivery, genes are delivered in two packages and they express two "halves" of a protein which are combined in the cell to form a full-length, functional protein to augment the missing protein. SpliceBio is targeting Stargardt disease, which is usually caused by mutations in ABCA4, a gene too large for current AAV gene delivery systems.

LEGACY

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6925 Oakland Mills Road, #701
Columbia, MD 21045

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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 www.FightingBlindness.org/Legacy-Newsletter

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"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

