LEGACY

SPRING/SUMMER 2023

A Publication for Supporters of the FOUNDATION FIGHTING BLINDNESS

FROM THE DESK OF JOHN R. CORNEILLE, J.D., LEGACY GIVING OFFICER

Spring Greetings to all,

I hope this edition of the Legacy newsletter finds you doing well and happy to have the winter of '23 behind us! I want to share my thoughts on legacy gifts and why they are so important to the long-term success of the Foundation and our mission – driving the research to find treatments and cures for inherited retinal diseases and age-related macular degeneration.

As the legacy giving officer, a volunteer, and someone affected with a retinal disease, specifically retinitis pigmentosa, I regularly receive outreach to contribute financially to our work on a current, ongoing basis. I respond when I can, with donations and keep abreast of the great strides and progress that financial support helps to achieve.

I have two daughters and three granddaughters, and while my primary concern when I am gone is to pass along what I have to them, I have also included the Foundation as part of my "family" by way of my own legacy gift. I have named the Foundation as a beneficiary of my 403(b) Retirement Account. My daughters know this, they understand, and are 100% supportive.

What is a legacy gift?

At the Foundation, we define a "legacy gift" as revenue that comes to us as the result of someone's passing. All of us, for the well-being of our families and to ensure our hard-earned assets end up going to whomever or whatever we decide, should be making end-of-life plans, even if those plans do not include a legacy gift to the Foundation.

The most common type of legacy gift remains bequests through someone's will or revocable living trust. Increasing in popularity and often the most tax-advantageous type of legacy gifts come by naming the Foundation as a beneficiary of beneficiary-designated accounts like IRAs, stock brokerage accounts, 401(k) retirement plans, and life insurance policies. A smaller portion (but often the largest from a dollar standpoint) of our legacy revenue comes from charitable remainder trusts.

Why is legacy gift revenue so important?

As alluded to above, not all of us can make large gifts to the Foundation in our lifetime. Everyone, however, can make a legacy gift in some amount. When you consider that we have thousands of people in our database, a legacy gift from everyone would be huge! The impact on our revenue, and thus our ability to fund research, would be transformational by even just doubling or tripling the number of legacy gifts received annually.

How can you help?

It is estimated that 50% of the people who die in the United States do so without a will, trust, or any type of estate plan in place. If you currently are one of the 50% of people without a plan, I encourage you to make one. As you consider that plan, please think about the impact that the Foundation has had on your life and how creating a legacy gift can help change the lives of future generations forever. If you have already created an estate plan, it is likely time to review that plan. When you do that, hopefully, your new plan will include the Foundation.

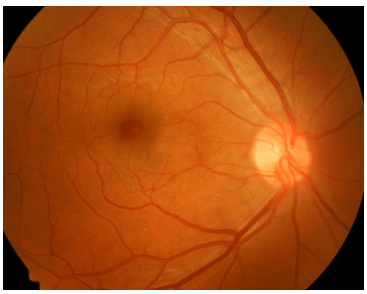
The Legacy Giving Team is here for you as a resource to answer questions and provide guidance as you contemplate a legacy gift.

Thank you all for your support of the Foundation. Together, we will win!

John

WHAT'S INSIDE

SPARINGVISION LAUNCHING CLINICAL TRIAL FOR CONE-PRESERVING TREATMENT



SparingVision, a French company developing therapies for ocular conditions including inherited retinal diseases, has received authorization from the U.S. Food & Drug Administration (FDA) to launch a Phase 1/2 clinical trial known as PRODYGY for SPVN06, its gene-independent, cone-preserving therapy for people with retinitis pigmentosa (RP). The company has also received authorization to conduct the trial in France. The U.S. trial will take place at the University of Pittsburgh Medical Center. The plan is to enroll a total of 33 RP patients who have disease-causing mutations in PDE6A, PDE6B, or RHO.

SparingVision is funded through the Foundation's RD Fund, a venture philanthropy fund for emerging therapies that are in or nearing early-stage clinical trials. The Foundation also provided several years of research grant funding for the preclinical development of SPVN06.

SPVN06 expresses a protein called rod-derived cone-viability factor (RdCVF), a naturally occurring protein in the retina identified by SparingVision co-founders José Sahel, MD, and Thierry Léveillard, PhD, at the Institut de la Vision. The scientists demonstrated in laboratory studies that RdCVF prevented or slowed the degeneration of cones, the cells in the retina that provide central and color vision and enable people to read, drive, and recognize faces. RdCVF is naturally secreted by rods, the retinal cells that provide night and peripheral vision.

SYFOVRE™ NOW AVAILABLE FOR TREATMENT OF GEOGRAPHIC ATROPHY SECONDARY TO AGE-RELATED MACULAR DEGENERATION

The U.S. Food & Drug Administration (FDA) approved SYFOVRE™ (pegcetacoplan injection) in February 2023 for people with geographic atrophy (GA) secondary to age-related macular degeneration (AMD), a leading cause of devastating central vision loss in people over 55 in developed countries. Developed by Apellis, the newly approved therapy is the first ever approved by the FDA for GA. SYFOVRE slowed the growth of lesions (areas of retinal cell loss) in two Phase 3 clinical trials. In the trials, known as DERBY and OAKS, the treatment was safe and its beneficial effect increased over time. More than 12,000 injections were delivered to trial participants over 24 months.

At 24 months in the OAKS trial (637 participants), monthly injections slowed GA lesion growth by 22 percent. Injections administered every-other-month slowed GA lesion growth by 18 percent.

At 24 months in the DERBY trial (621 participants), monthly injections slowed lesion growth by 18 percent. Injections administered every-other-month slowed lesion growth by 17 percent.

SYFOVRE is being delivered through an injection into the vitreous, the soft gel in the middle of the eye, once every 25 to 60 days in an eye doctor's office. Frequency of the injections will be at the doctor's discretion.

Apellis says that 90 percent of people eligible to receive SYFOVRE will be covered for it by Medicare.

GIFT PLANNING: AN ISSUE OF TRUSTS

Ways in which to plan for the financial security of visually impaired dependents

Being a parent or guardian certainly has its joys, but it's accompanied by anxieties as well – not the least of which is worrying about a child's future. That concern may be compounded when the child is someone affected by a retinal disease. How could it not be? Roughly two-thirds of the visually impaired who are eligible for employment are, in fact, out of work.

As someone affected by a retinal disease, I'm thankful to be gainfully employed, in part because I lost my vision gradually and was able to build a law career before I lost most of my useful vision. But things could have been much different for me. So, despite the very real promise of treatments and cures for retinal diseases, making financial plans for the future of your child, or any dependent, is important. I've had some experience in this area, as prior to joining the Foundation I was an attorney in the private practice of law for over 30 years, whose duties sometimes included acting as a state-appointed guardian for those incapable of supervising their own care.

There are many ways in which a visually impaired person's financial needs can be addressed, but for our purposes, I'd like to offer two recommendations involving trusts.

"Special Needs" or "Supplemental Needs" Trusts — These are designed to provide a fund for people who get financial assistance from the government, such as Social Security Disability and Medicaid, without disqualifying such people from receiving those benefits. The money put aside in the trust would go strictly toward necessities that government assistance does not completely cover – food, clothing, shelter, prescription drug costs, etc.

Upon the passing of the beneficiary, any funds remaining in the trust would be used to reimburse the government entity that provided assistance during the person's life. If any funds remain after that, they can be passed on to another person or a charity, such as the Foundation. But the primary motivation behind establishing such trusts is not charitable; it's to help ensure a person's quality of life.

"Charitable Remainder" Trust — This type of trust is, in part, charitable by nature but can also provide financial support for a dependent as well as significant tax advantages for the person setting up, and thus funding, the trust. In this case, the recipient's "income" – or the money supplied by the trust – would help determine just how much government assistance, if any, the disabled dependent needs. And after a specified number of years, or the passing of the dependent, the remaining funds would go to a designated charity or charities, not toward reimbursement of the government.

If you have questions about Legacy Giving or trusts, please contact the Foundation's Legacy Giving Team.

DID YOU KNOW?

Charity Navigator The Foundation Fighting Blindness is a 4-star charity on Charity Navigator, meaning the Foundation received a 90+ score, exceeding or meeting best practices and industry standards across almost all areas! Charity Navigator helps millions of people take action and support the causes they care about. Their comprehensive ratings shine a light on the cost-effectiveness and overall health of a charity's programs.

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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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IMPACT AND INSIGHTS

The Foundation Fighting Blindness is the world's leading organization committed to finding treatments and cures for blinding retinal diseases.

$891 MILLION

raised for retinal research and public health education since the Foundation Fighting Blindness began in 1971.

OVER 200,000

walkers, donors, and corporate sponsors have raised more than **$65 million** through VisionWalk.

80% of total expenditures this year have been spent on research and public health education.

OVER 270

retinal-disease causing genes identified.

MAJOR BREAKTHROUGH

LUXTURNA™ The first FDA-approved gene therapy for the eye or any inherited disease.

OVER 44 VOLUNTEER CHAPTERS

A national network that raises funds, increases public awareness and provides support to communities.

40+ CLINICAL TRIALS

launched for potential treatments.

40+ TOP CLINICAL CENTERS IN OUR CONSORTIUM

in the U.S., Australia, Canada, England, France, Germany, Italy, Israel, Mexico, and the Netherlands.

81 GRANTS FUNDED GLOBALLY IN 2022

• **105+** investigators • **70** institutions

RESEARCH PRIORITY AREAS

- **19.17%** Cell and Molecular Mechanisms
- **27.18%** Clinical: Structure and Function
- **15.90%** Gene Therapy
- **13.25%** Genetics
- **20.14%** Novel Medical Therapies
- **4.36%** Regenerative Medicine

1 IN EVERY 33

people in the U.S. are affected by a blinding disease.

RD FUND

Over $118 million raised through this venture philanthropy arm to accelerate late-stage outcomes through direct mission-related investments.

MY RETINA TRACKER® REGISTRY

Patient database with more than **24,000 profiles** – supporting the research community to actively collaborate and efficiently enable people to connect to relevant clinical trials.

FOUNDATION FIGHTING BLINDNESS

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 the key take-aways.

- The Foundation has played a major role in the development of 88% of treatments in clinical trials for the leading retinal 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 35% 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 trial 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.

May 2023

There is still much work to be done. Join the fight and help us accelerate our mission.
Visit **FightingBlindness.org** or call **800-683-5555**.