

LEGACY DONOR SPOTLIGHT: BARRY SMITH & EMILY HARDING SMITH

Barry and Emily met at the age of 17 while working at a grocery store. They have been together for 39 years, and Barry credits Emily as his primary source of support and inspiration to persevere.

Barry was diagnosed with retinitis pigmentosa (RP) while attending college, but his diagnosis came as no surprise.

“I had been experiencing symptoms at least as early as middle school,” Barry recalls. “By the time I was in high school, I was mature enough to understand I had the rare eye disease that affected my mother’s side of the family.”

Instead of asking for assistance, Barry hid the challenges he experienced and did his best to ignore the potential impact RP could have had on every aspect of his life.

“I had just watched my mother and grandfather lead successful lives and decided there was no reason I couldn’t do the same,” says Barry.

But after Barry completed college and graduate school, he was more honest with himself and the people around him.

“Hiding the impact of RP and attempting to live a ‘normal’ life was a heavy lift,” says Barry. When Barry felt like his vision loss was too much of a burden, Emily was there to support him.

Barry recognized the need to relinquish his car keys at the age of 32 when, on his way to work, the sun shining on a wet road caused a complete loss of visibility.

“It was a miracle that I did not cause an accident,” Barry recalls. “Eventually, I went back home and told Emily what happened. Emily grabbed her car keys and took me to work.”

She would continue doing so as Barry now approaches 30 years with his employer, Guideposts, a spiritual non-profit organization, publishing inspirational magazines, books, and online materials. As Director of Customer Service at Guideposts, Barry doesn’t think it’s a coincidence that he works for a company founded on hope, faith, and the power of positive thinking.

“Emily and I are neither doctors nor are we scientists,” says Barry. “But we can make a difference. I became aware of the Foundation Fighting Blindness through my mother and started supporting the organization as soon as we were financially able to do so. As we consider how to deploy and allocate our financial resources, it is difficult to imagine a better investment than the Foundation.”

When Barry reflects on his life since his RP diagnosis, he has no regrets and feels that his RP has made him an even stronger person.

“I have spent a lifetime attempting to prove what I can do, which has allowed Emily and I to be in a place where we can help. Please consider joining us.”



ABOVE: Emily and Barry smiling outside at the beach wearing sunglasses.

WHAT'S INSIDE ▾

Pg. 2 | IZERVAY Approved by FDA for Treatment of Geographic Atrophy Secondary to Advanced Dry AMD

First Patient Dosed in LCA5 Gene Therapy Clinical Trial Launched by Opus Genetics

Pg. 3 | I Created a Legacy Gift, Now What Do I Do?

VISIONS 2024

IZERVAY APPROVED BY FDA FOR TREATMENT OF GEOGRAPHIC ATROPHY SECONDARY TO ADVANCED DRY AMD

The U.S. Food and Drug Administration has approved IZERVAY™ (avacincaptad pegol) for the treatment of geographic atrophy (GA) secondary to advanced dry age-related macular degeneration (AMD). The treatment was developed by Iveric Bio, which was acquired by Astellas in July 2023.

IZERVAY is administered through monthly intravitreal injections — injections made in the soft gel in the middle of the eye — in a doctor’s office.

Astellas says that approximately 1.5 million people in the U.S. have GA.

“We are excited to have a new treatment for geographic atrophy which is a leading cause of devastating central vision loss for people 55 and older,” says Jason Menzo, chief executive officer, Foundation Fighting Blindness. “IZERVAY has the opportunity to help people maintain their independence and quality of life by preserving their ability to read, drive, and see faces of loved ones.”

IZERVAY met the primary endpoint, slowing the growth rate of GA lesions, in two global Phase 3 clinical trials. In the 448-participant GATHER1 clinical trial, IZERVAY slowed lesion growth by 27.7 percent at 12 months of treatment. In the 286-participant GATHER2 clinical trial, IZERVAY slowed lesion growth by 14.3 percent at 12 months of treatment. In both trials, patients were randomized to receive either 2 mgs of IZERVAY or a sham monthly.

IZERVAY is designed to work by inhibiting the C5 protein, which is part of the complement system. Researchers believe that the overactive complement system, part of the innate immune system, is a key culprit in the development of AMD. While the complement system plays an important role in fighting off viruses, bacteria, and other pathogens, it can be damaging when overactive.

Vision loss from GA is caused by the accumulation of toxic deposits underneath the retina called drusen. The condition can cause loss of retinal pigment epithelial (RPE) cells, which provide essential support for photoreceptors, the retinal cells that process light to make vision possible. The degeneration of RPE cells ultimately leads to loss of photoreceptors and central vision loss. In AMD, the macula, the central region of the retina, is affected most.

FIRST PATIENT DOSED IN LCA5 GENE THERAPY CLINICAL TRIAL LAUNCHED BY OPUS GENETICS

Opus Genetics, a company developing gene therapies for people with inherited retinal diseases, has dosed the first patient in its Phase 1/2 gene therapy clinical for Leber congenital amaurosis 5 (LCA5), which causes significant vision loss in children. The Phase 1/2 clinical trial, enrolling nine adult patients, is being conducted at the University of Pennsylvania. Once safety in adults has been established and confirmed by the U.S. Food and Drug Administration, Opus plans to dose pediatric patients.

Known as OPGx-001, the gene therapy uses a human-engineered adeno-associated virus (AAV) to deliver healthy copies of the LCA5 gene to the retinas of patients, augmenting the mutated copies causing vision loss. The therapy is administered through a one-time injection underneath the retina. Researchers believe gene therapies will be effective for many years, perhaps the life of the patient.

The LCA5 gene-therapy clinical trial is the first launched by Opus, a company originally conceived and formed by the Foundation Fighting Blindness. Founded in 2021, Opus received \$19 million in seed funding from the Foundation’s RD Fund, a venture philanthropy fund for emerging retinal disease therapies in or nearing early-stage clinical trials. The company is led by Ben Yerxa, PhD, former chief executive officer of the Foundation.

I CREATED A LEGACY GIFT, NOW WHAT DO I DO?

A “legacy gift” is a gift of money or property that comes to the Foundation as a result of a donor’s death. The most common type of legacy gift we receive continues to be through bequests in a will or living trust. However, a growing number of gifts are received by generous donors who have named the Foundation as a beneficiary to a number of different types of beneficiary-designated accounts, including retirement accounts, investment and brokerage accounts, life insurance, and even traditional checking and savings accounts.

Creating a legacy gift to benefit the ongoing work of the Foundation is, by its very nature, a very personal and selfless act. Think about it: gifts made upon your passing will never benefit you directly but instead will fund the research to help your children, grandchildren, and countless others who you will never know. As a person with severe vision loss from advanced RP, I created my own legacy gift by naming the Foundation as 100% beneficiary of my 403B retirement account. Through this simple act, I can think of no better way to make sure that future generations will never have to endure the real-life challenge of vision loss.

Once you have made the decision to name the Foundation as part of your lasting legacy, what is left to do? **It’s important to let us know.**

- It allows us to better plan for research in the future. While it is impossible to know when those legacy gifts will actually be received, the knowledge of what is likely to be in the pipeline of research revenue is important for us to know.
- It helps to ensure that your generous legacy gift will be received by us. Believe it or not, there are very few legal protections in the form of requiring life insurance companies and other beneficiary-designated account holders to notify named beneficiaries that the owner of the policy or account named them as a beneficiary. The result of this amazing truth is that hundreds of millions of dollars go undistributed to the intended beneficiaries. The problem is so prevalent that 60 Minutes devoted two separate segments to it several years ago. If you tell us your intentions, we will have that information to follow up on, ensuring your wishes are fulfilled.

- **It allows us to acknowledge and thank you.** If you create a legacy gift and never tell us about it, we only become aware after you are gone. Your gifts are deeply appreciated and critical to our ongoing mission, and we want to make sure you are properly acknowledged.

Please consider what the Foundation has meant to you and what including a legacy gift in your final plans will mean to future generations.

Circumstances in life sometimes dictate that not everyone is able to support the Foundation financially during their lifetime, but EVERYONE has the ability to leave a legacy gift, no matter the amount. Our goal is to someday rid the world of blinding retinal disease, and with your help, that day will come!

We are here to help.

John R. Corneille, J.D.
Legacy Giving Officer

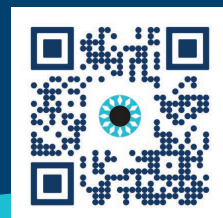
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Register today by visiting,
www.FightingBlindness.org/VISIONS2024.

JOIN US!



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