

FOR THIS LEGACY TEAM MEMBER, IT'S ALL ABOUT THE STORIES

At first glance, you might consider Kari VanderLaan's new role as Planned Giving Associate for the Foundation Fighting Blindness a stretch. What's someone with a degree in English and communications and a professional background in healthcare administration and education doing in the world of legacy giving, you might ask.

The connection couldn't be clearer to Kari.

"Legacy giving is so unique," she says. "It goes all the way back to my interest in English and communications. It's a kind of storytelling."

John Corneille, Director of Legacy Giving, says hiring Kari is a crucial step as the Reintsma 2025 Legacy Society leads more and more Foundation donors to consider legacy gifts.

"Adding Kari to the team and launching the Petrou Educational Initiative, which kicked off earlier this year at the VISIONS Conference," John said, "are just two parts of the Foundation's commitment to the generous legacy supporters who make up this important area of support."

Kari is honored to be a part of it.

"It's such a personal choice, and they are doing such an honorable, compassionate thing," she said of legacy donors. "I am here to help guide them through that decision, so they have the confidence to go out and make legacy plans that benefit their family and the Foundation."

Born and raised in Grand Rapids, Michigan, Kari graduated from Western Michigan University and worked in the healthcare field before joining the Navy, where she worked in human resources. Following her stint in the Navy, she worked in the education field, developing an interest in development which led her to the PETA Foundation.

It wasn't long before she got an opportunity to join the PETA fundraising team. A lot of that work was behind the scenes, but her interactions with donors got her curious about legacy work. When she came across the opportunity at the Foundation, it seemed like a great fit. She's been on the job since May.

"I've always approached all the work I do as an opportunity to reach out to people, make connections, and hear their stories," Kari said. "Everybody's got a story, and I think that's even more true for people who want to be legacy givers."

She says she's impressed with how responsive the Foundation board is and with how accessible the Foundation-supported science was for her as a new team member. It makes it easier for her to step into her education role, and it also supports the donor, says.

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ABOVE: Kari VanderLaan
Planned Giving Associate

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AFTER LOSING HER HUSBAND, DONOR WITH RP MAKES SIGNIFICANT LEGACY GIFT



ABOVE: Barbara outside at Carmel-by-the-sea, California.

Barbara Kensell has been slowly losing her sight for almost 60 years. Diagnosed with retinitis pigmentosa at age 10, she's learned well how to adapt. And when she lost her husband in April, she lost not only a life partner—she lost someone who helped her navigate the world.

But her husband Bob's passing has given her the opportunity to make an impact the couple was unable to make during their life together—to make a legacy gift to Foundation Fighting Blindness that will support research that could provide treatments and cures for future generations.

"My husband and I have not been able to be significant Foundation supporters during our lifetimes," she said, "but I would be honored to leave this gift as part of my legacy."

When Bob passed away at age 74, Barbara was the beneficiary of his IRA, which she has decided to leave to the Foundation.

"I needed to do something with it," she said. "Because we made that money. I wanted to do something, not while I'm alive because I'm unable to, but in my passing, I want to do something that will make a difference."

After her initial diagnosis, her mother told her very little about the condition, and even though she took part in an RP study at Stanford at 14, she didn't realize she would eventually lose her vision until she read a newspaper article about the condition at 18.

"My mother would say things like, 'I want you to get this

car when you're 16 because you may not always be able to drive,'" Barbara recalls. "I guess she kind of spoiled me or gave me different urgency to do things. But we never really talked about it."

As the condition progressed, she lost more and more peripheral vision and never drove at night. She was in her 20s before it really started to make an impact. She's always been able to adapt, but it got increasingly harder.

"There were things that were hard for me because no one knew my situation," she said. "It was on a need-to-know basis. No one at work knew, and I was able to kind of fake it."

Barbara is from the Bay Area of California—she was born and raised in Cupertino and lived most of her adult life in Walnut Creek. She and Bob met while commuting into San Francisco.

"They had bus service going from our community and from the little town where he lived, going into the city every 20 minutes," she said with a smile. "So, I met him on a bus."

She attended college for a couple of years in Saratoga but never graduated. Bob, who was several years older, had moved to the Bay Area from New Jersey, where he had worked for Bell Labs. She worked as a service manager for Jacuzzi, and he was a manager for Pacific Bell.

As an adult, she took part in Dr. Elliot Berson's well-known study of vitamin A and RP, which ultimately showed that a regimen of vitamin A, DHA, and lutein preserved vision in people with certain forms of RP.

She's able to read using inversion (white letters on a black background), and she can watch television, but she misses a lot. Losing Bob changed a lot.

"He was so good, and we worked together so well," Barbara said. "It was such a loss when he was gone because going back so many years, he would know things to point out. We would walk, and when we came to a curb, he would hesitate for a second, and then we would step down. We just worked. He knew how awful it was."

The decision to leave Bob's retirement account to the Foundation wasn't a hard one. She's lived with declining vision for years, and she's taken part in multiple studies.

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THE REINTSMA 2025 LEGACY SOCIETY FOUNDING MEMBERS

Since its creation in early 2021, the **Reintsma 2025 Legacy Society** continues to grow, ensuring funding for life-changing research into inherited retinal diseases will continue unheeded in the future. As Legacy co-chairs, we are excited to share with you that membership in the society has reached 66 members, representing more than \$33M in legacy gifts, easily surpassing the goal set in January of 2021. (You can see a list of all members on page 4).

It's a point of pride for us that the Foundation made legacy giving a priority when they included it in the Victory for Vision campaign goal. As a result, we have a team of engaged and committed volunteers who have spoken with nearly 300 legacy donors who shared compelling stories about why they decided to support the Foundation in this way.

You can read about one of those donors, Barbara Kensell, elsewhere in this newsletter. Barbara and her husband Bob weren't able to support the Foundation significantly during their life together, but she is proud to be able to make a significant legacy gift that honors their life together and Bob's devotion to her.

Like Barbara, we believe in the Foundation's mission, and we want to do everything we can to support it. We are both affected by inherited vision loss, 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,
David 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.

RIGHT:

The Reintsma
2025 Legacy
Society Badge



Founding Members

(as of October 3, 2022)

- Julie A. Anderson
- Steven C. and Ruth Ferris Armstrong
- Shari Arribere
- Peter and Stephanie Blaydes
- James and Brenda Buckley
- 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
- Barbara Kensell, in Honor of Robert Kensell
- James W. Kenst
- Boris and Saithong Lifshutz
- E. Benjamin Loeb
- Jason and Jole Lovelace
- James and Gayle Miragliotta
- In Honor of Frieda and Arthur Wyzanski
- Mr. and Mrs. Jim Luehrs
- Bob Morgenstern
- David Patrick Nixon
- Basil and Karen Petrou
- Don and Nita Reed
- Lori Rice and David Couzens
- Jane M. Sherwin
- In Memory of Joshua Andrew Skeen, II
- Martha Steele
- Jill R. Stone
- Mr. Phil Temples and Dr. Barb Cohen
- Otho Cox and Family
- Anne Vannice
- Eduardo A. and Sylvia Velasquez
- Adam L. Verchinsky
- Thomas S. and Sharon May Wallsten
- Susan and Art Weeden
- Clinton Woods
- 16 Friends of the Foundation – Anonymous

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“It’s wonderful to be able to tell them with confidence, ‘Here’s what’s being done for your specific condition.’ It gives them encouragement, and it reminds them how invested we are,” Kari said.

Over time, Kari expects she’ll also be wearing her storyteller’s hat more often.

“I certainly want everyone to be aware of the Foundation and what they’re doing and the great things that are happening. But when I’m speaking with a constituent, it’s about them,” she said. “They’ve got their legacy, and I think it’s such a lovely way to uphold their integrity and help them finish those later chapters of their story.”

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And she knows the Foundation will put the funds to the best use.

“I wanted to earmark it for RP, and I wanted it to go to research,” she said. “We chose not to have children, so this makes sense. Bob was so impacted by my vision loss that I think he would want nothing more than a cure or something that would slow the progression.”

And though she won’t live to see the impact of her gift, she’s positive it will make a significant difference.



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	Payout Rate
65	\$420.00	4.2%
75	\$540.00	5.4%
85	\$760.00	7.6%

Payout rates are effective as of July 1, 2022. This example assumes a \$10,000 gift. The annual payments shown are based on a onetime \$10,000 charitable gift annuity.

HOPE FOR RESTORED VISION THROUGH OPTOGENETICS

Optogenetics is emerging as one of the most promising and active areas of therapy development for people with advanced retinal degenerative diseases including those with retinitis pigmentosa, Stargardt disease, and age-related macular degeneration. Four clinical trials for the gene-agnostic approach are underway with additional alternatives moving toward human studies.

Designed for people who have lost most or all of their photoreceptors (the retinal cells that make vision

possible), optogenetics bestows light sensitivity to other cells in the retina, namely bipolar or ganglion cells, which survive after photoreceptors are lost. In essence, the bipolar or ganglion cells are used as a back-up system for photoreceptors.

Light sensitivity (i.e., restored vision) is made possible through delivery of gene copies that express light sensitive proteins to the retina cells.

SUMMARY OF SEVERAL CURRENT OPTOGENETIC RESEARCH EFFORTS:

Bionic Sight

In this company's Phase 1/2 clinical trial, patients with advanced vision loss from retinitis pigmentosa (RP) were able to see basic shapes and motion, and in some cases, color, after receiving the optogenetic therapy. Early results with the lowest dose showed one gentleman able to see candles after a one-time treatment via intravitreal injection. Another saw his dog running through the snow. Three patients who received higher doses have shown even more improvement, such as identifying shapes correctly more than 90 percent of the time in shape recognition tests and identifying colors correctly more than 80 percent of the time in color recognition tests. Bionic Sight's approach involves delivery of a microbial gene to ganglion cells for expression of a light sensitive protein. The user also wears special headwear designed to produce and deliver signals to the ganglion cells that are similar to signals generated by photoreceptors.

GenSight Biologics

In this company's Phase 1/2 clinical trial, a couple of participants with advanced vision loss from RP were able to locate and reach out to objects on a table. GenSight's therapy – a single intravitreal injection -- involves delivery of a microbial gene to ganglion cells for expression of a light sensitive protein. The user also wears goggles that boost the light signal going to the ganglion cells. The Foundation funded lab studies that helped make the GenSight trial possible.

Nanoscope Technologies

The company has launched two Phase 2 clinical trials in the US – one for RP, one for Stargardt disease – after reporting encouraging results from its clinical trial in

India. Nanoscope is delivering a gene via a single intravitreal injection to bipolar cells that expresses a protein (known as a multicharacteristic opsin) designed to provide greater light sensitivity than other microbial opsins. Therefore, the Nanoscope approach doesn't require glasses or goggles for boosting the light coming into the retina.

Kiora Pharmaceuticals

Kiora recently received authorization to launch a clinical trial in Australia for its vision-restoring photoswitch which is delivered to ganglion cells via monthly intravitreal injections. Because the emerging treatment is a chemical (not a gene), it is technically not optogenetic, though the approach is similar in concept to optogenetic therapies. The Foundation Fighting Blindness provided \$1.3 million in funding through its Translational Research Acceleration Program and a Gund Harrington Scholar Award to Richard Kramer, PhD, University of California, Berkeley, for the development of related photoswitches for restoring vision.

Vedere I and II

John Flannery, PhD, and Ehud Isacoff, PhD, at the University of California, Berkeley, have been developing optogenetic therapies that express a protein (medium wave green cone opsin) designed to work in natural light. Therefore, their approaches do not require eyewear. Their first incarnation of the approach, which was in preclinical development at the company Vedere I, was subsequently acquired by Novartis. Their second incarnation, which uses a photoswitch in combination with the opsin, is in preclinical development at Vedere II. The Foundation is invested in Vedere through its RD Fund, its venture philanthropy arm.

LEGACY

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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 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

