LEGACY

SPRING 2019

A Publication for Supporters of the FOUNDATION FIGHTING BLINDNESS

DONOR PROFILE

Meet Dan Day, one of the Foundation's many supporters directly affected with a retinal disease. In the article below, Dan will tell you, in his own words, why he has committed himself to the Foundation's mission and why, as a member of our Legacy Society, he feels it is important to include the Foundation as part of his lasting legacy.

Dan Day: Making a Difference Now and for Future Generations

by Dan Day, Legacy Society Member

I am one of over 10 people, spanning five generations, in my family affected by retinitis pigmentosa (RP). That includes my mother, two brothers, two nieces and a few of their children. I was diagnosed in 1978 at a Foundation Fighting Blindness funded lab in Boston. Today I am legally blind, but I consider myself fortunate that the disease did not begin to seriously diminish my vision until my late 20s, allowing me to participate in high school and college sports and to drive a car until I was 33 years old. Many of my family members were not so lucky and lost most of their vision as young adults.

Losing my vision and watching so many of my family members lose theirs was strong motivation for me to become involved with the Foundation. In 1990, I joined the local Orlando chapter and its fundraising efforts to support retinal disease research. Over time, I was honored to become the Foundation's Orlando chapter president and a member of the Board of Trustees. In 2015, I was proud to accept the Gund Challenge with the goal to drive research even faster.

Throughout my years of involvement with the Foundation, I have watched the amazing progress in understanding the causes of retinal disease and developing proven approaches for treating and curing these devastating diseases. At the Foundation's inception in 1971, very little was known about inherited retinal disease. Since then, mutations in more than 270 genes have been identified as underlying causes for these diseases.

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ABOVE: Dan Day speaking at the Orlando VisionWalk.

WHAT'S INSIDE

JOIN OUR MISSION

Help Us Build Our Legacy Society

Have you already included the Foundation Fighting Blindness in your will, trust, by beneficiary designation, charitable gift annuity, or some other aspect of your estate plan? If so and even if you told me in the past, please contact me so I can be sure you are properly included as a member of our Legacy Society. The Legacy Society is an elite group of very special, committed people who have informed us that they have included the Foundation as part of their lasting legacy.

Email me at JCorneille@FightingBlindness.org or call at (877) 254-6308, ext. 1.

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

Wills and Revocable Living Trusts are easy and flexible ways to leave a gift to the Foundation Fighting Blindness.

Please share this suggested language with your attorney:

"I give, devise, and bequeath the sum of $___ or ___ percent of my estate or specific asset to the Foundation Fighting Blindness, Inc., Tax ID #23-7135845. The Foundation Fighting Blindness is a 501(c)3 charitable organization located in Columbia, Maryland."

LATEST NEWS

Retinal Research Front Lines

First Patient Receives ProQR's Emerging USH2A Therapy in Clinical Trial

ProQR, a developer of RNA therapies in the Netherlands, announced that the first clinical-trial participant has received its emerging treatment, which targets retinitis pigmentosa and Usher syndrome caused by mutations in exon 13 of the USH2A gene. The Phase 1/2 clinical trial is taking place at Retina Foundation of the Southwest in Dallas and the University of Michigan in Ann Arbor. Known as QR-421a, the treatment is intended to slow or potentially reverse vision loss. The Foundation Fighting Blindness is investing up to $7.5 million through its RD Fund to move QR-421a into and through the early stage clinical trial. QR-421a is an antisense oligonucleotide (AON) — a small piece of genetic material — designed to mask exon 13 mutations in the RNA of USH2A.

The Foundation Fighting Blindness and Dr. H. James and Carole Free Collaborate to Combat AMD

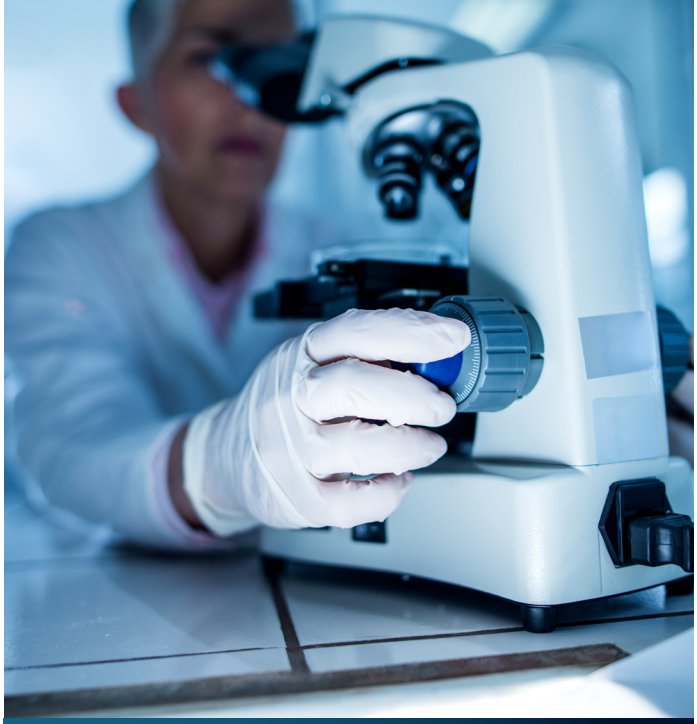
The Foundation Fighting Blindness has announced the launch of The Free Family AMD Research Program, which is providing funding for 10 research projects over five years for the development of age-related macular degeneration (AMD) therapies. With an anchor investment from Dr. H. James and Carole Free, along with legacy gift matching funds from the estate of James Lea, this new program will begin in July 2019. In addition to the new research being made possible by The Free Family AMD Research Program, the Foundation is also funding an additional $3.5 million for 11 other AMD research projects.

Encouraging Vision Improvements Reported in ReNeuron's Cell-Therapy Clinical Trial

ReNeuron, a cellular therapy developer in the UK, has reported vision improvements in the treated eyes of the first three retinitis pigmentosa (RP) patients in the Phase 2 part of the Phase 1/2 clinical trial for its proprietary human retinal progenitor cells (hRPC). The Phase 2 patients read an average of three additional lines (five letters per line) on a standardized eye chart after receiving the emerging treatment, compared to an average loss of one letter in their untreated eyes. The trial is being conducted at Massachusetts Eye and Ear in Boston and the Retinal Research Institute in Phoenix under the leadership of Jason Comander, MD, PhD, and Pravin Dugel, MD. The Foundation Fighting Blindness funded Michael Young, PhD, Massachusetts Eye and Ear, for pre-clinical and translational studies for the hRPC that helped make the ReNeuron trial possible.

Pixium's PRIMA Bionic Vision System Restores Central Vision in Dry AMD Clinical Trial

The French bioelectronics company Pixium Vision has reported that its PRIMA bionic vision system has restored some central vision in patients with advanced dry age-related macular degeneration (AMD) participating in a clinical feasibility trial. Led by Yannick Le Mer, MD, the study took place in the Department of Pr. José Sahel, Hopital des Quinze Vingts and Fondation Ophtalmologique A. De Rothschild, in Paris, France. At six months, a majority of patients, all of whom had no central vision upon trial enrollment, were able to identify complex patterns, numbers, or letters. Their speed and accuracy in identifying the visual information improved with rehabilitation. The system was safe and well-tolerated.



ABOVE: Researcher looking into a microscope.

Are you taking a Required Minimum Distribution this year?

A provision in tax law allows anyone over 70½ years of age to make donations to qualified charities directly from their traditional individual retirement account (IRA), tax-free! The law also applies to your required minimum distribution (RMD). The Foundation Fighting Blindness is one such qualified charity.

For more information, consult your tax advisor or the Foundation's Director of Legacy Giving, John R. Corneille, at 1-877-254-6308, extension 1 or JCorneille@FightingBlindness.org.

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As a result of the Foundation's efforts, a retinal prosthetic device is now generally available, and the first gene therapy for a retinal disease is FDA approved and available to cure one form of RP. In addition, over 35 clinical trials are in progress around the world for retinal diseases, encompassing approaches based on gene therapy, stem cells, and sight-restoring drugs. Though the Foundation does not directly fund every trial, those trials would not be possible without the knowledge born of early Foundation-driven research.

Perhaps the most powerful evidence of the Foundation's effectiveness in finding cures for retinal disease is that large numbers of commercial companies in the medical field are now investing significant capital into clinical trials. These companies are convinced that the approaches proposed by the Foundation have a high probability of success and will lead to cures and treatments. In short, experts around the world recognize the Foundation as the "best of the best" in the field of retinal disease.

All of this incredible progress is only possible because of those who have made a commitment to support the Foundation, including those who designate the Foundation in their legacy planning. Because I have seen such tremendous progress over the years and I want that progress to continue until the day when we have cures for all retinal disease, it is important to me that the Foundation be part of my lasting legacy.

I simply included the Foundation in my "Designation of Beneficiary" forms for my financial accounts and it only took a matter of minutes. Now that part of the legacy I leave for my nieces, their children, and my extended family in the Fighting Blindness community will be to help ensure that, in the future, no one will hear the words, "You are going blind and there is nothing we can do to help." I hope you will consider joining me as a member of Legacy Society by including the Foundation in your will, trust, or as a beneficiary of one or more of your beneficiary-designated types of accounts or assets.

Need More Information?

We are here to help, and we welcome your calls and emails if you have questions.

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

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The information in this document does not constitute legal or financial advice. You should discuss all of your estate planning questions with your own advisors before taking any actions.