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MAYA ANGELOU

FOUNDATION FIGHTING BLINDNESS

2018 Annual Report



THISIS WATER TO SERVICE TO SERVIC

THE FOUNDATION FIGHTING BLINDNESS DRIVES RESEARCH TO FIND PREVENTIONS, TREATMENTS AND CURES FOR PEOPLE AFFECTED BY RETINAL DEGENERATIVE DISEASES.





Hannah Reif is affected with Leber congenital amaurosis (LCA), a retinal disease causing severe vision loss and eventual blindness. In 2018, Hannah's vision was restored following treatment with LUXTURNA™ gene therapy.

Mike Valenti is affected with Usher syndrome, a combination of hearing loss and retinitis pigmentosa. He serves as President of the Foundation Fighting Blindness Philadelphia Chapter and Captain of Team Seeing Eye Lions for the Philadelphia VisionWalk.

A MESSAGE FROM **OUR CHAIRMAN** & CEO

THE FOUNDATION FIGHTING BLINDNESS PLAYS A CRITICAL ROLE IN THE FIGHT TO END BLINDNESS CAUSED BY INHERITED RETINAL DISEASE. WE ARE THE CATALYST IN FUNDING BREAKTHROUGH RESEARCH AND INNOVATIVE SCIENCE THAT PROVIDES PREVENTIONS, TREATMENTS AND CURES.

OUR RESPONSIBILITY

The Foundation Fighting Blindness strives to be a beacon of light in our community - guiding the way for inspiration and innovation. In addition to funding promising lab research for emerging treatments, the Foundation is the essential link between academia and industry. We find the best research on emerging treatments. We fund therapy development based on milestones. We help to protect researchers' intellectual property and we connect researchers with biotechnology and pharmaceutical companies for commercial development. Our mission remains the same since our founding in 1971 - driving the research that will bring an end to the entire spectrum of retinal degenerative diseases.

OUR PROGRESS

We are making tremendous progress towards achieving our mission. This was a milestone year with the first gene therapy for the eye or any inherited condition approved in U.S. history. LUXTURNA™ (voretigene neparvovec-rzyl) is gene therapy for the treatment of adult and pediatric patients with vision loss due to inherited retinal dystrophy caused by RPE65 gene mutations. Based on more than a decade of funding from the Foundation, this revolutionary therapy, marketed by Spark Therapeutics, restores sight to patients previously experiencing blindness (see page 6 for more information).

We are building on this success with new partnerships, scientific community interactions, fundraising events, educational programs, grassroots chapter activities and proactive outreach to Congress. Over the last year, we added a partnership with the biotechnology company ProQR to fund the clinical development of a novel potential treatment for Usher syndrome type 2A retinal disease. We formed a collaboration with CheckedUp, a point of care patient engagement company, to deliver patient-friendly diagnostic and disease-management information to people with retinal diseases. We participated in many key scientific forums, including hosting a workshop on two-year data findings from our ProgStar study on Stargardt disease and co-hosted the 5th Annual Retinal Cell and Gene Therapy Innovation Summit.

Through a combination of donor contributions and fundraising events, we raised \$23 million in Fiscal

Year 2018. During the year, we provided \$21 million for 79 projects at 67 prominent institutions and companies. There are now more than 33 clinical trials being conducted in the retinal disease area – a truly significant increase from three trials just 10 years ago. In addition, our team has supported the introduction of federal legislation, the Faster Treatments and Cures for Eye Diseases Act, H.R. 6421, that would create new financial instruments called Eye Bonds to provide research funding specifically designated for treatments and cures for all causes of blindness and severe vision loss (go to www.EyeBonds.com for more information).

OUR TEAM

All of this work is made possible by our incredible team of families, donors, volunteers, advisors,



Dr. Jason Comander, retinal specialist at Massachusetts Eye & Ear, with patient, Jack Hogan, following the landmark first post-approval surgery for LUXTURNA™ gene therapy.

EFIGHTING BLINDNES

FOUNDATION FIGHTING BLINDNESS INTRODUCES NEW LOGO

Beginning in January 2019, we will be launching a new logo. The decision to evolve the branding for the Foundation came out of a deep respect for our mission and the desire to build from our current brand in a way that clearly and strongly emphasizes our mission: Fighting Blindness.

The inspiration is entrenched in the idea that the Foundation is a beacon of light in the darkness. Both metaphorically, as a source of hope and inspiration, and also by "shedding light" on the complex subject matter of the science through public education initiatives. It is also quite a literal representation, as our mission is to find treatments and cures for blinding retinal diseases - literally bringing light to the darkness. We aspire to be a source of light in the darkness for the many individuals and families that we serve.

researchers, clinicians, government sponsors, corporate partners, board members and staff. Throughout this report we have featured pictures of our community members - these faces put meaning into everything we do.

Every two years we bring together this global community at our Visions Conference. We had record attendance this year in San Diego with a packed program of scientific presentations, clinical updates and patient-focused sessions. Importantly, we celebrated the tremendous commitment and accomplishments of our community members, including outstanding volunteer and researcher awards.

Over the past year we held more than 40 VisionWalk events and had team participation of more than 21,000 VisionWalkers raising funds to support research. In addition we are grateful for the contributions of our

Board of Directors, Scientific Advisory Board and Trustees - especially recognizing the many years of service by retiring Board member Marilyn Green.

OUR FOCUS

In the coming year, Foundation Fighting Blindness is targeting five key focus areas to continue adapting our organization and accelerating our ability to achieve our mission:

Increase Investment

We must expand our fundraising to allow for increased investment in translational research and clinical development while maintaining current investment levels in basic research.

Collaborate with Partners

We will work with new and existing academic, financial and corporate partners to support our march towards

"NEVER BEFORE HAS SO MUCH VISION-SAVING SCIENCE BEEN AT OUR DOORSTEP."

fulfilling our mission. These relationships are critical to delivering positive outcomes as quickly as possible.

Galvanize Our Community

We strive to deepen the connection to our grassroots working with patient families, chapters and volunteers to energize and bring our community together.

Enhance Communications

We will provide valuable information to our community and expand awareness to introduce new audiences to our mission while ensuring we apply best in class accessibility standards.

Evolve and Modernize Our Infrastructure

We need to make our operations as efficient as possible, so we can build on our success and accelerate progress.

In summary, we are committed to collaborating with our community to leverage our recent success and propel us into the future. Never before has so much vision-saving science been at our doorstep. The challenge is that these projects require millions of dollars in investment and thus our funding needs have grown exponentially. That's why we ask for the urgent support of our community. We need your help to continue bringing light where there is darkness.

Sincerely,

David Brint

Chairman

Benjamin Yerxa, PhD Chief Executive Officer



COLLABORATION AND INNOVATION RESULT IN SEEING

WITH FOUNDATION FIGHTING BLINDNESS

eeing stars, reading signs, recognizing faces of loved ones - these are lifechanging results from a therapy based on cutting-edge research funded by Foundation Fighting Blindness. For patients with retinal disease caused by RPE65 gene mutations, the approval of LUXTURNATM (voretigene neparvovec-rzyl) has opened a new world of vision.

As the first gene therapy for the eye to gain U.S. regulatory approval, this ground-breaking scientific achievement resulted from tremendous collaboration. For 47 years, the Foundation Fighting Blindness has been providing critical funding and support to researchers, clinicians and global organizations.

The success of an innovative therapy like LUXTURNA™ provides incentive to explore new approaches to treating many forms of blindness.

More than 20 gene therapy clinical trials are currently being conducted for retinal diseases, including X-linked retinitis pigmentosa, choroideremia, Usher syndrome type 1B, Stargardt disease, X-linked retinoschisis and

JACQUE DUNCAN, M.D. PROFESSOR OF CLINICAL OPHTHALMOLOGY UNIVERSITY OF CALIFORNIA, SAN FRANCISCO The medical team at Massachusetts Eye & Ear is able to deliver cutting-edge medical treatments to patients as a result of research and development funded by Foundation Fighting Blindness.

A COMMITMENT TO OUR COMMUNITY

VOLUNTEERS GATHER AT EVENTS ACROSS THE COUNTRY TO RAISE AWARENESS AND FUNDS FOR FOUNDATION FIGHTING BLINDNESS, INCLUDING 40 VISIONWALK FUNDRAISERS THAT PROVIDE A FUN AND FAMILY FRIENDLY OPPORTUNITY FOR COMMUNITIES TO COME TOGETHER IN SUPPORT OF FOUNDATION FIGHTING BLINDNESS.

NBC News anchor and Foundation Fighting Blindness National Trustee, Peter Alexander, cracked jokes with 12-year- old Brendan Friedrich, who garnered a	Delta Gamma volunteers provided enthusiastic support at the Cincinnati- Kentucky VisionWalk in September 2017.
standing ovation in June 2018 for his booming rendition of the Washington Capitals starting lineup announcement.	A great crowd gathered to watch the short documentary film, The Illumination, that highlights the stories of the Gund and Duwe families in dealing with inherited
Brad and Bryan Manning (co-founders of Two Blind Brothers clothing -	retinal diseases.
www.twoblindbrothers.com) were recipients of Visionary Awards at the May 2018 Fashion and Finance Ball in New York City.	Retinal development and regeneration expert, Thomas Reh, PhD, Professor of Biological Structure at the University of Washington, received the 2018 Ed Gollob
Mia Kee, Rebecca Fulton and Abby Grandin showed their team spirit at the successful VisionWalk in Montgomery	Board of Directors Award in June at the Visions2018 Conference.
County, Maryland that raised \$124,000 in September 2018, exceeding \$1 million raised over nine years.	Gordon and Lulie Gund engaged the audience at one of the many nationwide film screenings of The Illumination.
The Arizona VisionWalk had an impressive turnout that raised nearly \$100,000 in February 2018.	



Surrounded by friends and family, Ryan has taken a positive approach in dealing with the challenges of his disease.

yan Basso was 8 years old, playing third base, when a line drive abruptly ended his Little League career. He didn't stop playing because of pain or an injury. He gave up the game because he didn't see the ball coming at him.

Ryan had just been diagnosed with Stargardt disease, a form of macular degeneration that results in central vision loss. The effects of the inherited retinal condition can range from mild to severe. Doctors consider Ryan's case to be moderate.

> "I loved baseball. I played all the time," recalls Ryan, now a high school senior. "But I just couldn't see the ball.

That's when I knew I had to hang it up. It was time to quit."

But Ryan is by no means a quitter. He is a hardworking, accomplished student; he scored 32 out of 36 on his ACT college entrance exam and he's applied to eight highly competitive colleges.

Yet, there are challenges with significant vision loss. He needs accommodations at school and he is frustrated by not being able to drive.

"The driving situation is really rearing its ugly head, because all my friends are getting their licenses," he says. "I feel left out a lot. I want to be able to drive to my friend's house or get food, but I can't."



Ry's Guys team includes nearly 100 members that have raised more than \$36,000 for the Foundation Fighting Blindness.

The good news is his girlfriend, Alyssa, has her own car so he isn't exactly stuck at home alone all of the time.

One of the biggest challenges for Ryan and his family was getting a diagnosis and understanding what it meant.

The first sign of real trouble came when Ryan did poorly on a vision screening at school. The nurse called his parents, Stephanie and Mark, to let them know he had a problem with his vision. The family went to a local ophthalmologist who saw that something was in fact wrong with Ryan's retinas.

The ophthalmologist sent them to a retinal specialist at Mt. Sinai Hospital in New York City, who referred the family on to Dr. Stephen Tsang, a Foundation-funded clinical researcher at Columbia University. He confirmed Ryan's diagnosis as Stargardt disease caused by mutations in the gene ABCA4.

"My husband and I were devastated. We had no idea what the end result would be. We didn't know if he would be completely in the dark," recalls Stephanie. "We felt it was our fault, even though we knew we couldn't control our DNA and no one else in the family was affected. We still felt like we were responsible."

Shortly after the diagnosis, his family began searching for help, leading them to Foundation Fighting Blindness.

"We received a lot of encouragement and support from the Foundation," says Stephanie. "We joined the Westchester-Fairfield chapter, but not until two years after the diagnosis, because we weren't ready yet to move forward."

Ryan's family formed their VisionWalk team, Ry's Guys, in 2010, drawing a remarkable wave of support that has been growing every year.

"At first we were surprised by how many people got involved. It has become a community event in a way. Our team includes family from Florida, Ryan's friends, our daughter Casey's friends and Ryan's teachers," says Stephanie. "My husband's family has been strongly committed to the walk since the beginning. And, last year, his company, Command Financial, made us their annual charity."

Stephanie's sisters, Lisa and Amy, serve as chairs for the walk, while Ryan and his cousins, Brooke and Jess, are the youth chairs. Stephanie credits their prize drawing for generating a lot of interest and enthusiasm. Prizes have included: hotel packages, a stay at a bed and breakfast, dinners at upscale restaurants, sports tickets and collectibles, cases of wine and candy baskets. The drawing raised about \$7,000 in 2017.

"It is incredible to see nearly 100 people come out on walk day to support me and my cause. It is such a wonderful event - raising money for research," says Ryan.

Ryan is excited about the research. His experience with retinal disease has inspired him to explore a career as a biomedical engineer. He is working on a Stargardt science project at school, being mentored by Dr. Winston Lee, a retinal research fellow at Columbia.

When it comes to his future, Ryan says, "I'm taking it one step at a time. Sometimes I think about how I am going to get around in college – what I will use for transportation. But for the most part, I tackle challenges as they come." With such a strong team supporting him, Ryan is bound for success.

HIGHLIGHTS OF 2018 RESEARCH INVESTMENTS

EACH YEAR, THE FOUNDATION FIGHTING BLINDNESS ALLOCATES SUBSTANTIAL FUNDING TO CUTTING-EDGE SCIENTIFIC RESEARCH, THE DEVELOPMENT AND CLINICAL TESTING OF INNOVATIVE TREATMENTS AND CAREER DEVELOPMENT OF PROMISING PHYSICIANS AND SCIENTISTS.

In Fiscal Year 2018, Foundation Fighting Blindness provided \$21 million in total retinal research funding for 79 projects at 67 prominent institutions and companies. Listed below are highlights of the new investments made during Fiscal 2018.

PARTNERSHIP INVESTMENT IN THERAPY FOR USHER SYNDROME TYPE 2A (\$7.5 MILLION)

The Foundation Fighting Blindness has entered into a partnership with ProQR to develop a retinal therapy for people with Usher syndrome type 2A (USH2A) caused by mutations in exon 13 of the USH2A gene. The Foundation will be investing up to \$7.5 million in milestone-based funding to advance the treatment, known as QR-421a. ProQR's therapy is an antisense oligonucleotide (AON), which works like "genetic tape" to repair the mutation. While this novel treatment approach is for a specific mutation in USH2A, it may have applicability to a broad range of diseases.

INDIVIDUAL INVESTIGATOR AWARDS (\$2.1 MILLION)

Gene Therapy to Preserve Vision by Protecting Cones

Daniel Lipinski, PhD, Medical College of Wisconsin. This treatment may help people with retinitis pigmentosa,

Usher syndrome, and other conditions that affect cone photoreceptors.

Designing Optimal Viral Gene-Delivery Systems for Retinal Diseases

Leah Byrne, PhD, University of Pittsburgh. This research may help people with a broad spectrum of retinal diseases.

An Optogenetic Therapy with Improved Light Sensitivity

John Flannery, PhD, University of California, Berkeley. The treatment is designed to help people with advanced vision loss from retinitis pigmentosa, Usher syndrome, and other advanced retinal diseases.

Inhibiting Immune Response to Transplanted RPE Cells

Trevor McGill, PhD, Oregon Health & Science University. The knowledge gleaned from this study may help people with different forms of macular degeneration.

VLC-PUFA Therapeutics for Dry AMD and Dominant Stargardt Disease

Paul Bernstein, MD, PhD, University of Utah. This potential treatment would hopefully slow the progression of vision loss.



Identifying Genetic Modifiers that Affect Severity of Stargardt Disease

Frans Cremers, PhD, Radboud University Medical Center, Netherlands. Knowledge gained from this research would potentially give researchers new targets for therapies.

Large Animal Model Development for Usher syndrome 1B

Martha Neuringer, PhD, Oregon Health & Science
University. This model of disease would be beneficial for
testing treatments before they move into human studies.

GUND-HARRINGTON SCHOLARS (\$1.8 MILLION)

CRISPR/Cas9 gene editing delivered as nanoparticles

Krishanu Saha, PhD, University of Wisconsin-Madison. This promising treatment approach may help people with a broad spectrum of retinal diseases.

Nanoparticle-based gene therapy for Stargardt disease (ABCA4)

Zheng-Rong Lu, PhD, Case Western Reserve University. Nanoparticles could potentially be a safe and effective approach for delivering therapeutic genes.

CAREER DEVELOPMENT AWARDS (\$1.4 MILLION)

Mandeep Singh, MD, PhD, assistant professor in ophthalmology, Wilmer Eye Institute, Johns Hopkins Medicine, is investigating transplantation of cones derived from embryonic stem cells for vision

restoration. The treatment may help people with different forms of macular degeneration.

Shyamanga Borooah, MBBS, PhD, Shiley Eye Center, University of California, is testing CRISPR/Cas9 geneediting (gene-correction) in human cells and animal models of autosomal dominant diseases affecting retinal pigment epithelial cells.

Rachel Huckfeldt, MD, PhD, Massachusetts Eye & Ear, Harvard, is investigating the causes of the potentially harmful collection of fluid associated with cystoid macular edema (CME), as well as better ways to treat it. CME is common in people with retinitis pigmetnosa, Usher syndrome and retinoschisis.

Nieraj Jain, MD, Emory Eye Center, Emory University, is investigating a retinal dystrophy associated with chronic use of the interstitial cystitis drug pentosan polysulfate sodium.

Marta Stevanovic, Howard Hughes Medical Institute Research Fellow, University of Oxford, is studying CRISPR/Cas, a novel gene-editing technology that has the potential to correct DNA mutations that cause ocular disease.

Sean Wang, Howard Hughes Medical Institute Research Fellow, Harvard Medical Institute, is investigating the role of microglia as a therapeutic target for a broad range of inherited retinal degenerative diseases.

\$750 MILLION+

>75 RESEARCH **PROJECTS**

33 CLINICAL TRIALS

>268 **GENES**

1ST GENE THERAPY

APPROVED BY FDA FOR THE EYE



A MESSAGE FROM OUR TREASURER

I am pleased to provide you the statement of activities and financial position for the Foundation Fighting Blindness' fiscal year ending June 30, 2018.

For the year, we outperformed our planned budget with revenue and support of \$23 million, operating expenses of \$11 million and research funding of \$21 million.

We are grateful for the generous support of our donors who continue to support the Foundation each year. Our strong financial position is due in part to the substantial funds raised through the Gordon and Llura Gund Family Challenge, as well as continued grassroots fundraising by individuals and their networks of family and friends.

Most of the research programs we fund include activities and milestones that span multiple years and many of the donations we receive are multi-year pledge commitments. Under nonprofit accounting principles, this multi-year aspect impacts our statement of financial position in two ways.

First, our audited financial statements indicate we have future obligations for grant payments of \$7 million. However, we have binding commitments and reserves for identified, milestone-based research spending totaling \$41 million. The funding for the additional \$33 million in grant commitments is

subject to certain scientific milestones; under generally accepted accounting principles, these obligations may not be reflected as liabilities on our balance sheet until the milestones are met. If any milestones are not met, the funds committed to that research will be redeployed into other research.

Second, accounting rules require that for multi-year pledges, we record all pledged revenue in the years the pledges are made rather than as the pledges are actually paid or as research projects are funded. As a result, the funding of research projects creates a deficit for the current fiscal year even when the projects are funded out of contributions collected during the same year.

In summary, the Foundation has the financial resources and strategic partnerships within the inherited retinal disease research community to continue to make significant investments to fulfill our mission and serve as a beacon of light in our community.

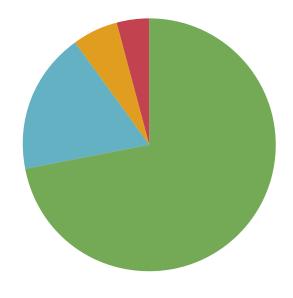
With heartfelt thanks to all our donors, volunteers, staff and researchers.

ms P. Lan

Haynes P. Lea Treasurer

STATEMENT OF ACTIVITIES

FISCAL YEAR ENDING JUNE 30, 2018		2018
REVENUE & SUPPORT		
Contributions	\$	7,795,000
Special Events, Net of Direct		6,410,000
Bequests		7,741,000
Other Revenue		1,206,000
Total Revenue	\$	23,152,000
EXPENSES		
Research	\$	20,550,000
Public Health Education		2,324,000
Administration		2,565,000
Fundraising		6,563,000
Total Expenses	\$	32,002,000
Total Change in Net Assets		(8,850,000)



FISCAL YEAR 2019 TARGET SPENDING ALLOCATIONS

72%
RESEARCH
INCLUDING
GRANTS

18% FUNDRAISING

6%
PUBLIC HEALTH
EDUCATION

4%
ADMINISTRATION

STATEMENT OF FINANCIAL POSITION

FISCAL YEAR ENDING JUNE 30, 2018		2018
ASSETS		
Cash and Investments	\$	101,556,000
Pledges Receivable, Net		29,203,000
Other Assets		1,878,000
Trusts and Other Funds		7,924,000
Fixed Assets, Net		1,385,000
Total Assets	\$	141,946,000
LIABILITIES		
Accounts Payable and Accrued Liabilities	\$	1,853,500
Research Grants Payable		6,842,000
Deferred Revenues		904,500
Liabilities Under Trusts and Other Funds		1,513,000
Total Liabilities	\$	11,113,000
NET ASSETS		
Total Net Assets	\$	130,833,000
Total Liabilities and Net Assets	\$	141,946,000

NATIONAL CHAPTERS

FOUNDATION FIGHTING BLINDNESS CHAPTERS REACH OUT TO AFFECTED INDIVIDUALS AND THEIR FAMILIES WITH INFORMATION, SUPPORT AND ENCOURAGEMENT. THERE ARE MORE THAN 40 VOLUNTEER-LED CHAPTERS IN THE U.S. THAT HOST A VARIETY OF EVENTS CRITICAL TO THE FOUNDATION'S SUCCESS.

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FOUNDATION FIGHTING BLINDNESS NATIONAL TRUSTEES ARE LEADERSHIP-LEVEL VOLUNTEERS WHO SUPPORT THE FOUNDATION'S FUNDRAISING, ORGANIZATIONAL DEVELOPMENT AND VOLUNTEER RECRUITMENT EFFORTS.

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THE FOUNDATION FIGHTING BLINDNESS SCIENTIFIC ADVISORY BOARD IS COMPRISED OF MORE THAN 50 OF THE WORLD'S LEADING RETINAL EXPERTS WHO PROVIDE INSIGHT ON RESEARCH AND CLINICAL ADVANCEMENTS AND REVIEW RESEARCH GRANT APPLICATIONS.

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