

# FOUNDATION FIGHTING BLINDNESS

ANNUAL REPORT 2015



RISING *TO THE CHALLENGE*

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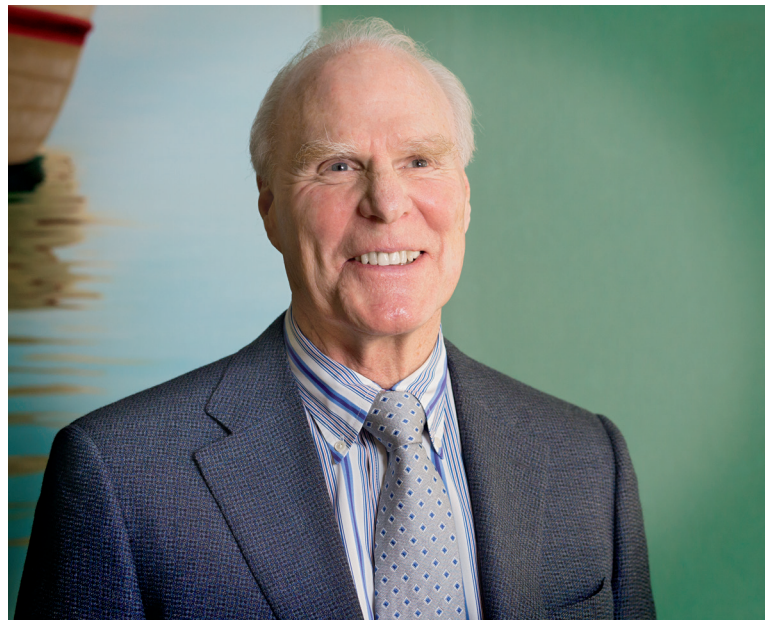
*An unprecedented fund-matching campaign and an increase in clinical-trial activity made last year exceptional—and highlights the need for increased funding.*

Looking back on this fiscal year, the Foundation Fighting Blindness (FFB) takes great pride in raising more revenue for retinal research than ever before. This accomplishment was due to the relentless commitment of members, volunteers and donors like you.

Our year began July 1, 2014, roughly a week after we announced The Gordon and Llura Gund Family Challenge, a dollar-for-dollar campaign that matches new and increased donations of \$25,000 or more. The goal is \$100 million or more by June 30, 2016.

With seven months remaining, we are pleased to announce that the Challenge has surpassed the \$65 million mark—a share of which is reflected in fiscal year 2015 revenues. Thank you for helping to kick off the Challenge so generously. And while it's an impressive sum, we won't stop until we raise at least the remaining \$35 million. In this Annual Report, we celebrate the many achievements of the past year and promote the Challenge and its vital role in helping to capitalize on the unprecedented research momentum of the past few years.

For a visual representation of that momentum, check out the research timeline (“An Acceleration of Vision-Saving Breakthroughs”) on pg. 3. It's followed, on pages 5-6, by two Q&As with donors who share why the Challenge resonates with them



*Gordon Gund, Chairman and Co-Founder*

(“Taking Up the Challenge”). One is an individual, the other a representative of a fellow nonprofit focused, in part, on health-related issues.

Both interviewees make great cases for the historical significance of the Challenge—primarily that the retinal-research field, after four decades of development, is now poised to produce treatments. The latest example is a recent announcement by Spark Therapeutics, developer of a gene therapy for Leber congenital amaurosis (LCA), that results from Phase III of its clinical trial are positive. The company—whose work was facilitated, in part, by Foundation funding—is now preparing for U.S. Food





*Bill Schmidt, Chief Executive Officer*

## A MESSAGE FROM THE CHAIRMAN AND CEO

and Drug Administration market approval, hopefully sometime next year.

In the words of a Challenge donor, it was FFB's early investment in the LCA therapy, when commercial investors weren't yet convinced of its efficacy, that helped "de-risk" the treatment. The same can be said of the Argus II "bionic retina" as well as several other treatments now moving toward clinical trials and backed by companies reassured by the Foundation's endorsement. It's worth noting that these treatments are not limited to gene therapies; they include stem-cell and pharmaceutical therapies and next-generation prosthetics.

Included in this report are research and events highlights from the past year ("Mission-Related Milestones," pg. 8) and a full financial statement delivered by our Board treasurer (pages 9-10). But we'd both like to remind you that the funds required each year are increasing the closer we get to moving treatments to the marketplace.

The primary reason behind The Gordon and Llura Gund Family Challenge is to raise the stakes to highlight the urgency of this latest stage of our mission. Next year will mark the 45<sup>th</sup> year that we've been in business. And as you've probably heard us say before, our goal is to put ourselves out of business—that is, to deliver the cures that ensure no one goes blind due to retinal diseases.

That goal is no longer just a hope; it's now becoming a reality. But it's a goal that will not be fully realized until we've done all we can to achieve it. This is why we're asking those who can meet the Challenge to step up and do so—before June 30, 2016 arrives, knowing that every dollar you give, and every matching dollar that follows, will directly support the cutting-edge research that has brought us to this historic moment.

We know that you're with us for the long haul, and we appreciate your continued support.

Sincerely,

**Gordon Gund**  
Chairman and Co-Founder

**William T. Schmidt**  
Chief Executive Officer

# AN ACCELERATION OF VISION-SAVING BREAKTHROUGHS

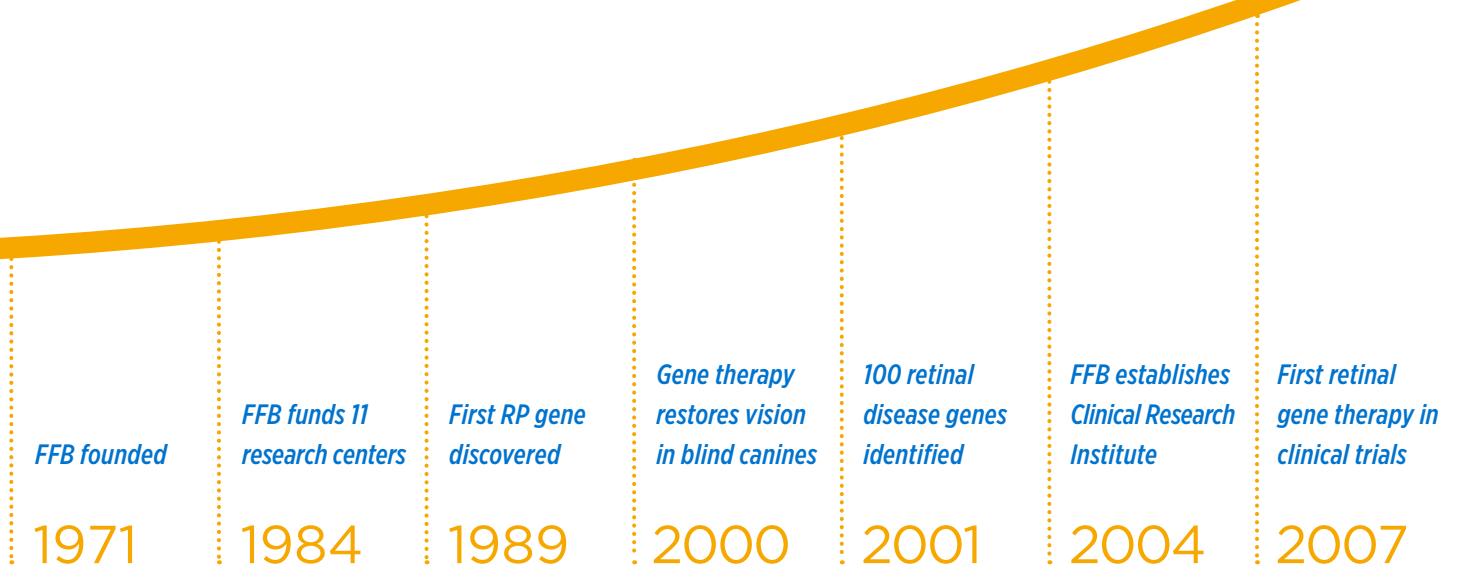
*FFB spent 35 years building a strong scientific foundation, which, leading into the past decade, has paved the way for a retinal-research revolution. But its work is far from over.*

When a few impassioned families created the Foundation Fighting Blindness (FFB) in 1971, neither they nor the first FFB-funded researchers knew how difficult it would be to find the root causes of vision loss, let alone develop treatments and cures. It took until 1989 to find the first gene mutation for retinitis pigmentosa (RP).

But that was just the beginning. By 2001, more than 100 retinal-disease-causing genes had been discovered—for RP, Usher syndrome, Stargardt disease and other inherited diseases. No one dreamed that more than 250 genes would be identified by 2015, with dozens more yet to be found.

But these discoveries led to a better understanding of why diseases occur and the development of lab models for testing potential therapies. Success in the lab in the early 2000s ultimately opened the door to clinical trials. And thanks, in part, to vision restoration in the first gene-therapy clinical trial launched in 2007, we are now experiencing a new era of human research and commercial development.

That, of course, is the good news, and it's reflected in the accompanying timeline. But with the entire spectrum of retinal conditions yet to be eradicated, and the eyesight of tens of millions of people worldwide on the line, FFB has much more work to do.



Today:

20

clinical trials for inherited  
retinal diseases

12

companies developing  
therapies for  
inherited retinal  
diseases

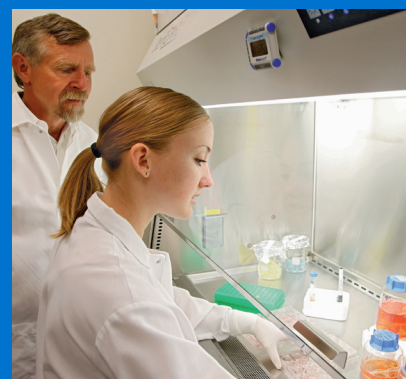
2

FDA-approved wet  
age-related macular degeneration  
therapies

ARGUS II

first FDA-approved  
bionic retina

2015



## TAKING UP THE CHALLENGE

The Gordon and Llura Gund Family Challenge is the Foundation's way of leveraging unprecedented momentum in retinal research. And, so far, it's working.

Just before Fiscal Year 2015 began, the Foundation Fighting Blindness' co-founder and chairman of the board, Gordon Gund, made a startling announcement. Over the next two years, through June 30, 2016, he and his wife, Lulie, would match all qualifying donations of \$25,000 or more given to the Foundation. And he referred to this matching campaign, appropriately enough, as The Gordon and Llura Gund Family Challenge.

Why a "challenge?" Because researchers, informed by four decades' worth of scientific advances facilitated by the Foundation, are poised to move multiple treatments for retinal diseases into clinical trials. But their endeavors, closely observed by companies and venture capitalists alike, can't be accomplished without capital. Which is why all of the Challenge funds will directly support research.

The Foundation's goal is to raise at least \$100 million via the Challenge. As of this writing, 130 generous Challenge donors have brought that tally to more than \$65 million. So with roughly half a year left, the Foundation needs additional donations to help close that \$35 million gap.

In the Q&As on these pages, two donors share the reasons they contributed to the Challenge and explain why meeting the Foundation's goal is so vital to its ongoing mission.

For details about The Gordon and Llura Gund Family Challenge, including ways to contribute, contact:

**Hope Kessler**  
**Senior Director, Major Gifts**  
**212-244-1470**  
**hkessler@fightblindness.org**



### YVONNE WONG CHESTER

***"When you look at it, the Gunds' generosity is unmatched. So you join in the fight, to your maximum ability."***

Yvonne Wong Chester, a Napa, California resident with retinitis pigmentosa (RP), has 8 degrees of vision. That's compared to the roughly 180 degrees those with normal vision enjoy. But Chester's not complaining. "I would be so happy," she says, "if I could keep these 8 degrees and not lose any more."

Which is one reason she recently donated \$25,000 to The Gordon and Llura Gund Family Challenge, a dollar-for-dollar match making her gift worth \$50,000, all of it going to retinal research. It was FFB's focus on research that led Chester, in 1997, to the Foundation, where she's served as a national trustee and board member.

Today, the former attorney—who was born in Hong Kong, grew up in San Francisco and lived most of her adult life in Los Angeles—is witnessing a research renaissance. "It's amazing progress," she says of the 20-plus treatments now entering clinical trials. "I could not have imagined we'd come this far so soon."



### When were you diagnosed, and how has vision loss affected your life?

I was 39. Before that, I didn't notice any visual problems. I just assumed everybody couldn't see in the dark and that, in tripping over things, I was clumsier than most. And there wasn't anyone in my family I knew of with retinal problems. But my optometrist, during one visit, got really excited and said, "Look at this pigmentation!" He sent me to a retinal specialist, and my RP diagnosis was confirmed.

I had about 30 degrees of vision then. After a few years of it getting worse, I stopped driving and quit the job I'd had for 18 years, as an attorney in corporate and securities law. I loved my job, but my vision was too poor to read all that fine print. And not being able to drive in L.A. to get clients? Forget it!

### How did you get involved with FFB?

As soon as I was diagnosed, I did all the research I could and, through a business contact, concluded that I needed to align myself with the Foundation. I liked its emphasis on research—focusing on the source of the problem. And when I had to retire, I told FFB's Los Angeles office that I wanted to become even more involved. That led to my becoming a trustee and, eventually, Secretary of the Board.

When it comes to research, I've been genetically tested but don't yet know which gene mutation is causing my RP. So I'm interested in "universal" treatments, where you don't need to know the gene—optogenetics, in particular.

But here's what impresses me. If you think back 45 years, to when the Foundation was born, there was nothing out there—no retinal specialists, no treatments. I am in awe of the vision Gordon Gund and his co-founders had. They created a great business model: they invest in the best research in its early stages, when commercial investors think it's too risky, so that researchers have the time and resources to develop what they're working on. They "de-risk" projects, and it pays off.

(See "Chester," page 7)

### WILLIAM J. CHATLOS, JR.

***"It's a tremendous opportunity. It makes good business sense. It certainly makes a lot of philanthropic sense."***

William J. Chatlos, Jr. was just 14 years old when he got the bad news from an eye doctor. Only he couldn't quite make sense of it. After he returned home from his check-up, his mother asked how it had gone. He told her, "I have rollo scoliosis, and I'm gonna go blind." What he meant to say was "retinitis pigmentosa," or RP, which in 1960 was not only hard to pronounce; it was a big mystery. There were no RP experts at the time, and certainly no hope for treatments or cures. "And I still had good vision then," Chatlos recalls. "So I was thinking, I'll be old anyway—it doesn't matter if I go blind."

Fast-forward to 2015. Chatlos is 69, almost completely blind ("I can see light and dark") and CEO and president of The Chatlos Foundation, Inc., a nonprofit originally founded by his grandfather which, over three decades, has contributed more than \$8 million to the Foundation Fighting Blindness. That includes a recent five-year, \$625,000 gift which qualifies for The Gordon and Llura Gund Family Challenge—a match campaign that brings the donation's total value to \$1.25 million.

(See "Chatlos," page 7)



Chester  
(cont. from pg. 6)



Look at the Argus II, the retinal prosthesis. FFB funded it very early on, when nobody else would or even believed in the idea. Now look where it is—approved by the FDA, helping people around the world.

The same has happened with other entities, including the company AGTC, which is putting together three clinical trials for different treatments. So, really, we're just getting started.

### **Is that why you contributed to The Gordon and Llura Gund Family Challenge?**

When you look at it, the Gunds' generosity is unmatched. And when you see that kind of unselfish generosity, you want to be a part of it. So you join in the fight, to your maximum ability.

I'm giving \$25,000. I personally feel that is low because I used to be in a different financial position. If I still was, I would have given a lot more. But I am giving what I can at the moment. And I'd recommend that, while the Challenge is going on, everyone else should do the same.

Chatlos  
(cont. from pg. 6)



### **The recent Chatlos Foundation gift benefits research, correct?**

Yes, it does. Usually, our grants are for raising awareness. Because of my personal experience, and because

most of the retinal diseases FFB targets are "orphan" diseases, meaning they affect 200,000 people or less, many people just don't know what retinitis pigmentosa is or Usher syndrome, or any of the other retinal degenerations. So we want to make people aware.

But Gordon came to me and asked about the possibility of the Chatlos Foundation getting involved in the The Gordon and Llura Gund Family Challenge, and I told him I'd present it to our board. We don't normally give multi-year commitments because of our relatively small size. But we couldn't pass up the opportunity to capitalize on the match and make a big impact at such a crucial time.

### **Since your involvement with FFB in the 1970s, you've served as a national trustee and a board member. What has been the organization's most significant progress to date?**

I remember discussions, early on, where people said, "If we can find just the one gene mutation that causes retinitis pigmentosa, we will be on our way."

And we honestly thought at the time that there was only one. And now we're at more than 200 genes identified, for various types of RP and allied types of retinal diseases. There are so many, I can't keep track of them.

And of course we're in the midst of all these clinical trials for treatments. A gene therapy for Leber congenital amaurosis has restored vision in children in clinical trials, and the Argus II "bionic retina," funded early on by FFB, enables completely blind people to detect light.

That's part of the genius of FFB—its multi-disciplined approach. There's not just one avenue if treatments look promising. FFB and its Scientific Advisory Board, which is second to none, are investing in gene therapy, pharmaceuticals, prosthetics and cell transplantation.

### **What would you say to anyone who hasn't yet given to The Gordon and Llura Gund Family Challenge?**

It's a tremendous opportunity. Any time a person can leverage his or her interest, and have people like Gordon and Lulie match that, it just makes a lot of sense. It makes good business sense. It certainly makes a lot of philanthropic sense. I would encourage anyone who has that opportunity and the funds available to join FFB in improving people's lives.



## 2015 MISSION-RELATED MILESTONES

### Fundraising & Outreach



*VisionWalk entered its 10<sup>th</sup> year.*

#### VisionWalk - \$38 Million, 10 Years and Counting

During Fiscal Year 2015, several of the Foundation's VisionWalks, its signature 5K fundraisers, hit their 10<sup>th</sup> year and, by the end of the spring season, helped push the collective program's total beyond \$38 million. Nationwide, there are more than 40 annual VisionWalks and 100,000 participants, all of them helping to fund critical research.



*VISIONS 2015 speaker Rebecca Alexander*

#### VISIONS 2015 in Baltimore

Nearly 600 people from around the world attended the Foundation's national conference, VISIONS 2015, in Baltimore, Maryland. For three days, participants attended informative sessions, networked and had fun. Among the highlights—a keynote delivered by Rebecca Alexander, author of *Not Fade Away*, and awards ceremonies honoring dedicated researchers and volunteers.

### On the Local Front

Local fundraising and public-education efforts contribute as much to retinal research as FFB's national and global efforts. And during the past year, Foundation members in 47 chapters across the country attended speaker seminars and social gatherings and participated in dining, personal-campaign and sporting events.

### Research

#### Another Choroideremia Clinical Trial Launched

Earlier this year, the Philadelphia-based company Spark Therapeutics became the second of three research teams, within 18 months, to launch a clinical trial for a gene therapy targeting choroideremia. The other trials are taking place in England and Canada. Spark is the company also known for its development of an LCA gene therapy that will be submitted for FDA market approval in 2016.

#### A Trailblazing RP Stem-Cell Therapy

A clinical trial the Foundation helped organize for a treatment it funded in its pre-clinical stages was given the go-ahead by the FDA. Conducted by the company ReNeuron, it is the first-ever clinical trial for an RP stem-cell therapy and involves the injection of cells beneath the retina, where they'll hopefully develop into functional photoreceptors. Dr. Eric Pierce, former chairman of FFB's Scientific Advisory Board, is the trial's lead investigator.

#### Bionic Retina, Next Generation

Second Sight, creator of the Argus II, or bionic retina, is developing a new device designed to bypass the eye altogether and link directly to the brain. In doing so, the device, known as the Orion I, has the potential to restore vision in people affected by various diseases, not just RP. Second Sight hopes to launch a clinical trial in 2017.

# 2015

## A MESSAGE FROM OUR TREASURER

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We are pleased to present the [Statement of Activities and Financial Position for the Foundation Fighting Blindness' fiscal year that ended June 30, 2015.](#)

The Foundation had an exceptionally productive year, raising more than \$59 million in revenue, the highest annual amount raised in the organization's 44-year history. This success is due in large part to The Gordon and Llura Gund Family Challenge, a dollar-for-dollar match of all qualifying donations of \$25,000 or more as part of our Envision 20/20 Campaign.

Envision 20/20 is a major-gifts campaign designed to raise substantial funds to fuel what is now unprecedented research momentum by the end of this decade. We are very pleased with the success of the Campaign thus far. The goal of the Challenge is to draw \$50 million in new and additional pledges by June 30, 2016. Matched by the Gunds' contribution, that would bring the Campaign's total to more than \$100 million.

With that said, not all Campaign funds are being invested immediately. Two years ago, our Research Oversight Committee—comprised of esteemed scientists, FFB board members and experienced drug-therapy developers—evaluated the potential of current retinal-disease research in gene therapy and cell transplantation as well as emerging developments in optogenetics and neuroscience. The committee formulated a strategic plan that calls for the Foundation's investment of \$20 million per year for lab-based science research, translational research and proof-of-concept research—the pre-clinical investigative work that will lead to clinical trials and, ultimately, FDA-approved new treatments. A large portion of Campaign funds are being reserved to meet the research funding outlined in that strategic plan.

Meanwhile, the Foundation performed well outside the parameters of the Envision 20/20 Campaign. We spent roughly \$20 million on research and public-health education during the 2015 fiscal year, and, as always, awarded grants to a variety of promising projects ranging from gene therapies to stem-cell and pharmaceutical treatments. Thanks to the diligent efforts of the Foundation's Clinical Research Institute, more than 20 other treatments are already in clinical trials or being prepared for them.

Fiscal Year 2015 was also a big year for our VisionWalk program, which includes more than 40 annual 5K walkathons taking place across the country. The handful of walks that kicked off the program in 2006 celebrated their 10<sup>th</sup> year this past spring, and by the year's end, collective revenues from the program surpassed \$38 million.

We mentioned in last year's report that the Foundation had recently launched a free, online patient registry known as My Retina Tracker™. It is a vital resource for enrolling patients in clinical trials and getting treatments from the labs to patients. We encourage everyone to make use of My Retina Tracker™ if they haven't already and spread the word to other Foundation members. Registration is easy and can be done at [www.myretinatracker.org](http://www.myretinatracker.org).

Note that even after The Gordon and Llura Gund Family Challenge ends, we will continue to encourage friends and associates to give all they can to facilitate the treatments and cures those affected with retinal diseases deserve. Our ongoing resolve, boosted by the generous Challenge, will help ensure that we do not falter in our progress.

Sincerely,



**Haynes P. Lea**

Treasurer

## 2015 Research Grants

In its relentless, ongoing mission to find preventions, treatments and cures for the entire spectrum of inherited retinal degenerative diseases, the Foundation Fighting Blindness funds a diverse research portfolio focused on six priority areas: genetics, gene therapy, cellular mechanisms of diseases, clinical-structure and function relationships, novel medical therapy and regenerative medicine.

During fiscal year 2015, the Foundation and its Clinical Research Institute provided approximately \$14.6 million in support of 113 grants, including those for 14 collaborative research centers. The funded research projects are being conducted by 187 research investigators at 69 institutions, eye hospitals and universities within the United States and abroad, including laboratories in China, England, France, Germany, Italy, Israel, the Netherlands and Switzerland.

- Research Center grants totaled \$5.4 million
- Individual Investigator Research grants totaled \$5.3 million
- Alan Laties Career Development Program grants totaled \$821,000
- FFB Clinical Research Institute clinical studies and grants totaled \$3.1 million

**For details on individual grants, including project descriptions and disease relevance, visit the interactive Financials section of the online version of this report at:**  
[www.FightBlindness.org/2015AnnualReport](http://www.FightBlindness.org/2015AnnualReport).

## Statement of Activities 2015

### REVENUE AND SUPPORT

Contributions	45,382,000
Special events, net of direct	8,120,000
Bequests	3,066,000
Other revenue	2,584,000
<b>Total revenue</b>	<b>59,152,000</b>

### EXPENSES

Research	17,091,000
Public Health Information	2,107,000
Management	2,325,000
Fundraising	7,166,000
<b>Total Expenses</b>	<b>28,689,000</b>

Change in unrestricted net assets	7,266,000
Change in restricted net assets	23,197,000
<b>Total change in net assets</b>	<b>\$30,463,000</b>

## Statement of Financial Position

### ASSETS

Cash and investments	\$77,833,000
Pledges receivable, net	23,486,000
Other assets	1,133,000
Trusts and other funds	8,204,000
Fixed assets, net	1,998,000
<b>Total Assets</b>	<b>\$112,654,000</b>

### LIABILITIES

Accounts payable and accrued liabilities	\$2,674,000
Research grants payable	7,430,000
Deferred revenues	189,000
Liabilities under trusts and other funds	1,477,000
<b>Total Liabilities</b>	<b>11,770,000</b>

### NET ASSETS

Unrestricted net assets	9,498,000
Unrestricted net assets for research	6,621,000
Temporarily restricted net assets	84,265,000
Permanently restricted net assets	500,000
<b>Total net assets</b>	<b>100,884,000</b>
<b>Total liabilities and net assets</b>	<b>\$112,654,000</b>



# FOUNDATION FIGHTING BLINDNESS

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[www.FightBlindness.org](http://www.FightBlindness.org)

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