

Foundation Fighting Blindness 2008 Annual Report

# Let there be Light



## WORKING TO SAVE, RESTORE, AND PROTECT YOUR VISION

The Foundation Fighting Blindness is urgently driving the research that will one day end vision-robbing retinal degenerative diseases.

Since 1971, the Foundation Fighting Blindness has raised more than \$300 million in support of its mission to find preventions, treatments, and cures for blinding conditions such as macular degeneration, retinitis pigmentosa, Stargardt disease, and Usher syndrome. Collectively, these diseases affect more than 10 million people in the United States.

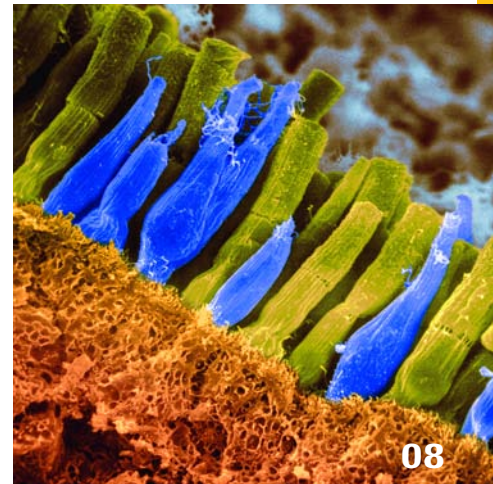
The Foundation is the largest non-governmental supporter of retinal disease research in the world.

Thanks to funding from the Foundation, human studies are now underway for gene therapy to cure blindness in children. Later-stage clinical studies of a tiny capsule that has the potential to save vision are also being conducted for retinitis pigmentosa, macular degeneration, and Usher syndrome.

The Foundation funds innovative research in a number of scientific areas including genetics, gene therapy, stem cell therapies, neuroprotection, and nutrition at prominent institutions around the world.

Thanks to the Foundation's tireless efforts, all people with retinal degenerative diseases have hope for a future without blindness.

# Let there be Light



## FEATURES

### 04 **A Ray of Light: Advocacy and Events**

Helping patients and their families find the answers they need to help them deal with the challenges of retinal diseases and to live productive, fulfilling lives.

### 08 **2008 Research Highlights**

From landmark gene therapy that restored vision, to phase II/III clinical trials for vision-saving capsules.

### 10 **Little Charmer**

Three-year-old Lily suffers from Leber congenital amaurosis, but the Gaboras have great hope for her future.

### 12 **Unbreakable Bond**

The Hajjar family has faith that an emerging treatment will halt or reverse the effects of Usher syndrome.

### 14 **Visionary, Entrepreneur, and Pioneer**

Ebby Halliday Acers is well-recognized for her business achievements. But she is also renowned for being a true philanthropist — giving back generously.

### 02 **CHAIRMAN AND CEO LETTER**

### 16 **2008 RESEARCH GRANTS**

### 28 **GIVING TO THE FOUNDATION**

### 30 **TREASURER MESSAGE**

### 31 **2008 FINANCIAL STATEMENT**

### 32 **LEADERSHIP**

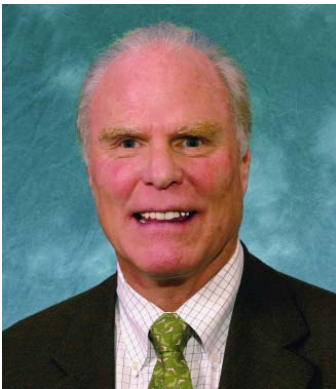
### 1B **CHAPTERS**

## ON THE COVER:

Lily Gabora, as  
photographed by  
Ed Caldwell

# A Year of Breakthroughs

Earlier this year, we reported the most important research breakthrough in FFB history. The achievement was heralded



**Gordon Gund**  
*Chairman  
on Behalf of the Board*



**William T. Schmidt**  
*Chief Executive Officer  
on Behalf of the Staff*

as one of the greatest ever made in retinal research. FFB and hundreds of major media outlets around the world announced that gene therapy restored some vision in three young adults who were virtually

blind from a severe form of retinitis pigmentosa known as Leber congenital amaurosis. The breakthrough was made through an FFB-funded clinical trial at The Children's Hospital of Philadelphia. Human studies of similar treatments at the Universities of Pennsylvania and Florida and Moorfields Eye Hospital reported vision improvements, as well. As you might expect, we are absolutely delighted with these results, and the promise they bring for saving and restoring vision.

One remarkable aspect of this treatment is that the corrective gene is delivered by injecting a tiny drop of liquid underneath the retina. Given results from preclinical studies, researchers believe that a single injection may be effective for many years — quite possibly a lifetime. Of course, decades of work went into development of the treatment, but the simplicity of it is extraordinary. It almost seems like something out of a science fiction movie, especially given where the science was when FFB was established in 1971.

But this is the essence of our mission: making vision-saving treatments simple, easy, and accessible to everyone. Imagine if a child diagnosed with retinitis pigmentosa, Stargardt disease, Usher syndrome, or choroideremia could walk into a doctor's office and walk out with a treatment or a cure. Maybe the treatment would be one simple injection. Maybe it would involve implanting a tiny capsule like the Neurotech device and replacing it every few years. Perhaps a disease-halting eye drop would be prescribed.

Imagine if every ophthalmologist in our country could identify someone at risk of age-related macular degeneration and prescribe an eye drop or a pill that would prevent the disease from ever robbing them of their vision.

For the family of people who make up the Foundation Fighting Blindness — the organizational leaders, donors, corporate partners, chapter leaders, VisionWalkers, and Dining in the Dark patrons — this is our goal. This is why we give. This is why we organize and partner. This is why we educate our friends, family, and co-workers about retinal degenerative diseases and their vision-robbing effects. And this year, thanks to your unwavering determination, we crossed a critical threshold when those three young adults began to read lines on an eye chart. As Dr. Mort Goldberg said at our VISIONS Conference in Washington, D.C., "We have entered a golden era in the treatment of retinal degenerative diseases." Dr. Goldberg, who leads our National Neurovision Research Institute (NNRI) to move promising treatments into clinical trials, is one of the great retinal science visionaries who have helped bring us to this promising juncture.

The momentum we bring to 2009 is strong. Our revenues and memberships are at their highest levels ever. The participation in our walks, dinners, and events is growing. Chapters are expanding. More potential treatments are in clinical studies than ever before. The Foundation's research budget has doubled over the last three years. And, NNRI has established numerous partnerships with biopharmaceutical companies to move promising treatments out of the laboratory and into the clinic as quickly as possible.

Thanks to the extraordinary generosity of an anonymous donor, we launched the Translational Research Acceleration Program, a five-year commitment to quickly advance a number of highly promising treatments — including neuroprotective, stem cell, and pharmaceutical therapies — into clinical studies.

However, much work lies ahead. Clinical trials cost tens of millions of dollars. The work involved in advancing the research is painstaking. Each step forward requires a tremendous amount of focus and persistence. We have many more scientific and financial hurdles to clear before we reach the day when blinding retinal degenerative diseases will be completely eradicated.

Please take a moment to review this annual report to learn about the many achievements we have made this year in the fight against blindness. And for the many of you who have made these victories possible, we applaud and thank you.

As we move into 2009, we need your energy and enthusiasm more than ever before. More sight-saving and sight-restoring breakthroughs will not be possible without your continued hard work and support. As a member of the FFB family, you share our vision of treatments and cures for the millions affected by retinal degenerative diseases in our country and around the world. Thank you for being a part of the FFB family, and for working with us into 2009 and beyond. Thanks to your efforts, we'll have more and more breakthroughs to share in years to come. Thanks for being the light for the millions who would otherwise face a future of darkness.

HELPING PATIENTS AND FAMILIES THROUGH

# EDUCATION, ADVOCACY AND EVENTS



## Speeding the Pace

What are the latest treatments on the horizon for my disease? How can I connect with other parents who understand what I'm going through? What can I do to help find a cure? While funding research to find treatments and cures is our key mission, each and every day, all across the country, the Foundation Fighting Blindness is helping patients and their families find the answers they need to help them deal with the challenges of retinal diseases and to live productive, fulfilling lives.



“Working with the Foundation is about taking control of these diseases. Getting engaged in the battle to find treatments, preventions, and cures empowers us to make a difference, not only for our generation, but for future generations.”

Jim Platzer, FFB Chapter President, Ft. Wayne, Indiana

### Staying Connected

Our newly designed and organized website, [www.FightBlindness.org](http://www.FightBlindness.org), offers patients critical information personalized to their needs. Web surfers can visit disease-specific pages, learn about clinical trial information, coping resources, and local events. Website visitors can also make a donation, read stories of hope, and find details about a local chapter.

In addition to new easier navigation features, the state-of-the-art website now has the capability to read content aloud and enables users to change background colors and font sizes for easier reading. The website also brings people together for mutual support. Patients, families and friends are sharing their personal stories on the site’s message boards and chats. The site is proving to be a valuable resource for patients and has grown to more than 80,000 visitors each month.

### Extending Our Reach

By reaching out to the media, hosting symposia and conferences, and partnering with retinal specialists across the country, the Foundation provides an important service to those affected. Programs have been developed all over the country to meet the needs of patients, families and professionals – the people who deal with blinding diseases every day.



Nancy Kerrigan,  
with Bill Schmidt

The Foundation has worked with media in providing information to those affected through television, radio and newspaper stories. This year, the Foundation was featured in hundreds of newspaper, television and radio stories across the world when three patients with LCA had their vision restored through gene therapy (see story page 8). In addition, throughout the year, our signature events such as VisionWalk and Dining in the Dark, as well as other local events, generated impressive media coverage in numerous markets.

Radio public service announcements (PSAs) are another effective way for the Foundation Fighting Blindness to reach hundreds of thousands of people all across America affected by retinal degenerative diseases. In 2008, Foundation PSAs were played at radio stations nationwide encouraging listeners to attend local FFB-sponsored seminars or to call a toll-free phone number to obtain a comprehensive, free information packet for themselves or for a family member or friend.

The Foundation’s 2008 VISIONS Conference in Washington, D.C. brought together more than 600 people from around the country to hear about the latest research for retinal degenerative diseases, learn about daily living strategies and the latest technology for the visually impaired, and network with others. In addition to sessions conducted by world-renowned researchers, attendees were also treated to presentations by world champion figure skater Nancy Kerrigan, Congressman Pete Sessions, and actors Jon Wellner (CSI) and David Chisum (One Life to Live).



Chelsea Van  
Dueck and  
Pamela Paterson

Attendees participated in a wide range of sessions and activities and came away informed, inspired and optimistic about the future. Talk of on-going clinical trials dominated many of the conference's presentations and discussions.

This past year FFB continued its Vision Seminar Series bringing much-needed information to local communities. During these one-day symposia, held at eleven locations around the country last year, doctors discussed the latest treatments and research for retinal diseases, and low-vision specialists presented tips and tools to help people cope with vision loss. Fifteen symposia are scheduled for the upcoming year. This series is supported by Genentech, Founding Partner of FFB's National Corporate Partners Program.

When someone is diagnosed with a retinal disease, it can be hard to know where to turn for information. Over the past year, the Foundation partnered with dedicated retinal specialists all across the country to provide resources and support for patients at the time of diagnosis or during subsequent eye exams.

### **Genentech, an innovator as FFB's Founding Corporate Partner**

In an effort to fulfill its urgent mission to find cures and treatments for retinal diseases and improve the lives of people affected by these conditions, FFB has created its own National Corporate Partners Program. Leading the charge as the Founding Partner of this program is biotech innovator **Genentech**, headquartered in South San Francisco.

As the Founding Partner, Genentech will have a presence at all FFB signature events across the country as well as inclusion in FFB publications, marketing collateral and the newly re-launched website at [www.FightBlindness.org](http://www.FightBlindness.org).

We salute Genentech for working with the Foundation to find cures for these diseases and to provide critical information to those affected. With the help of national corporate partners, FFB is able to support researchers who are bringing us closer to cures for these vision-robbing diseases. For more information on the National Corporate Partners Program, contact us at [corporatepartnership@FightBlindness.org](mailto:corporatepartnership@FightBlindness.org).



**Above: (left to right) Haris Syed Ahmed, Rashida Ahmed, Raheela Shaffie, Tariq Shaffie.**

**Bottom: (back row, left to right) Marilyn Merrill, Trent Merrill, Robin Paterson, Renee Thomas. In front is Billy Curtis.**



### **A Leading Source of Information**

The Foundation keeps its members abreast of advances in the field of retinal research through various publications and resources. FFB provides educational booklets and brochures on a variety of diseases including treatment options and scientific advances, low vision and support resources, and genetic testing information.

Our Information and Referral Department and our off-site call center field thousands of calls each month from people requesting information about retinal degenerative diseases.

Additionally, during the past year, more than 130,000 households received our newsletter, *InFocus*, and tens of thousands of people read about the latest breakthroughs via *InSight*, our electronic newsletter, sent out five times a year.

“FFB is important to me, because they are a leader in supporting research for a cure. Also, FFB has established local chapters, which are bringing people together to share information, offer support, and raise money to speed the pace of critical research.”



Gilesa Black, FFB Chapter Member  
Charlotte, North Carolina

### A Voice in Washington

Our advocacy efforts help shine the spotlight on issues important to our members — building awareness of the need for legislation to fund research and patient education and assistance programs. In 2008, through letter writing campaigns, personal visits to Capitol Hill, and Congressional briefings, we increased funding for the National Institutes of Health, which in turn means increased funding for the National Eye Institute, which can ultimately translate into additional resources for retinal degenerative disease research. In addition, thanks to many of your emails and requests to your senators and representatives, the Genetic Information Nondiscrimination Act was approved. This law protects Americans against employment and health insurance discrimination based on their genetic information.

Through our online grassroots advocacy program, we are continuing to build a loyal network of supporters who are ready to champion the issues most important to FFB.

### Connecting Through Chapters

FFB has 50 chapters around the country reaching out to affected individuals and their families with information, support, and encouragement. These volunteer-led chapters host a variety of meetings and events and are critical to FFB’s fundraising success. See the back page of this report to find a chapter near you.



Dining in the Dark event in Orange County, California

### Events

Thanks to the efforts of thousands of volunteers across the country, the Foundation hosts hundreds of events throughout the year. From our signature events such as Dining in the Dark Visionary Award Dinners, and 42 VisionWalks, to our unique online Race to Cure Blindness fundraising program, golf tournaments and wine tastings, these special events are an important way to raise critical funds for research. To learn more about the Foundation’s events throughout the country and how you can get involved, visit our website at [www.FightBlindness.org](http://www.FightBlindness.org) and click on the Chapter box on the left.



**LOG ON NOW!**  
[www.FightBlindness.org](http://www.FightBlindness.org)

# A Year of Remarkable Progress Now They See!

## Landmark Gene Therapy Restores Vision

Three young adults who were virtually blind from a severe form of retinitis pigmentosa known as Leber congenital amaurosis are now able to read lines on an eye chart and see in dimly lit settings thanks to an FFB-funded clinical trial of an innovative gene therapy at The Children's Hospital of Philadelphia. Participants in clinical studies of similar treatments at Moorfields Eye Hospital and the Universities of Florida and Pennsylvania also experienced improvements in their vision. The breakthrough was hailed as the greatest in FFB's history and was covered by hundreds of media outlets around the world including *Good Morning America*, *CNN*, and the *Associated Press*. Researchers are optimistic that vision improvement will be even more dramatic in children who receive the treatment. Success in these studies is paving the way for the development of gene therapy to treat a variety of other retinal conditions including: Stargardt disease, Usher syndrome, choroideremia, retinoschisis, and other forms of retinitis pigmentosa.



“Funding from the Foundation has helped us push forward quickly to develop a gene therapy that is restoring some vision for people with LCA. This will open the door for developing treatments, and perhaps cures, for a wide variety of vision-robbing retinal diseases.”

Jean Bennett, M.D., Ph.D., University of Pennsylvania, Children's Hospital of Philadelphia

### Gene Therapy Development Efforts Underway for Stargardt Disease

Two gene therapy collaborations are providing tremendous hope for people with Stargardt disease. FFB and Oxford BioMedica, a biopharmaceutical company in the United Kingdom, are planning to launch a clinical study of an emerging gene therapy for Stargardt disease in 2009. The new treatment employs a lentivirus for gene delivery and shows excellent potential for halting vision loss from Stargardt disease.

FFB is also funding a collaboration between The Children's Hospital of Philadelphia and the "Federico II" University in Naples, Italy, to develop a gene therapy for the treatment of Stargardt disease and other conditions. Their therapy uses an adeno-associated virus for gene delivery. The team is planning to launch a clinical study in 2010.

### Research Collaboration Advancing Gene Therapy for Usher Syndrome

A promising gene therapy to halt vision loss from Usher syndrome type 1B – a devastating disease that causes both blindness and deafness – is being developed by

FFB-funded scientists from the University of Florida, University of Pennsylvania, and the University of California. The investigators are planning to launch a clinical trial for the treatment in late 2010.

### Partnership with Genable Takes Aim at Dominant Retinitis Pigmentosa

The Irish biopharmaceutical company Genable is making excellent progress in silencing the genes that lead to autosomal dominant forms of retinitis pigmentosa. FFB and Genable have established a partnership to advance gene therapy for dominant forms of retinitis pigmentosa into a clinical study in 2010. The emerging treatment employs small interfering RNA (siRNA) to shut down the defective genes that cause progressive vision loss in dominant RP.

### Phase II/III Trial Results Coming for Vision-Saving Capsule

In spring 2009, Neurotech will report results for their clinical trials of encapsulated cell technology (ECT). More than 150 people are enrolled in studies of the tiny implantable capsule – the size of a grain of rice – that may be effective in saving and even restoring vision in people with a variety of retinal degenerative diseases including: age-related macular degeneration, retinitis pigmentosa, Usher syndrome, and choroideremia. The capsule provides sustained release of a protein that shows potential for keeping the retina healthy, and ultimately, saving and restoring vision. Neurotech has received fast

track approval for the treatment, which provides a quicker route to FDA approval, if clinical trial results are favorable. FFB is funding two of the current Neurotech clinical studies, and funded pivotal preclinical research of the ECT.

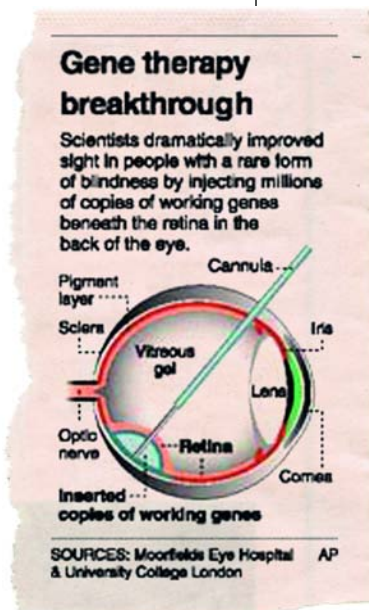
### Stem Cell Advancements Provide Hope for Retinal Rescue and Regeneration

The Foundation is making a significant investment in stem cell research, because emerging stem cell treatments are showing great potential for slowing or halting

vision loss caused by retinal degenerative diseases, as well as replacing retinal tissue damaged by disease. In preclinical studies, investigators have developed retinal cells from embryonic stem cells, and facilitated their integration into the retina. Scientists are also developing stem cells to enable a person's own tissue – skin, for example – to ultimately be turned into retinal cells.

### Scientists Develop Pivotal Model for AMD

A new animal model for age-related macular degeneration – a model that closely represents the condition in humans – gives biopharmaceutical companies an invaluable platform for the development of therapies that can stop the disease process at an early stage, before any vision is lost. The mouse model was developed by Foundation-funded scientists from the Cleveland Clinic, Cole Eye Institute.



Greg and Kristine Gabora, with daughters Lily and Chloe





# Little Charmer

UP CLOSE: LILY GABORA

Lily Gabora was born a healthy and beautiful eight-pound girl. Her parents, Kristine and Greg, were delighted to bring home their second child, and Chloe, their first child, was thrilled to have a brand-new baby sister.

However, shortly after Lily came home, the Gaboras knew that something was not quite right with her vision. They noticed unusual eye movements, and that she wasn't making visual contact the way their first daughter had as an infant. "I wasn't getting the deep gazes from Lily during nursing time that I got from Chloe," recalls Kristine.

When Lily reached nine months of age, Kristine and Greg decided to take her back to the doctors to better understand what was happening with Lily's eyes. They were ultimately referred to a retinal specialist, who gave a definitive, but devastating diagnosis. "Lily is completely blind," he said. "She has Leber congenital amaurosis. There is no cure."

"We were in complete shock. It was the longest hour-and-a-half drive home," Kristine tearfully remembers.

The Gaboras were quick to get Lily all of the resources and training she needed to live well and succeed. In addition to going to preschool, Lily has a teacher for the visually impaired, as well as mobility and orientation training. She's now learning how to use a cane.

"She's really blossomed," says Kristine. She exceeds most children in cognitive skills, memory, and vocabulary. When people talk to her they say, 'You're not three, you're thirteen!' Lily is a charmer. She lights up the room. You just want to be around her. She's friendly, funny, silly, and likes to rough house – she's a dare devil, too! She knows every genre of music. The other day, while listening to the car stereo, she said, 'Listen, daddy. It's Earth, Wind, and Fire.' "

In addition to helping Lily navigate the sighted world, the Gaboras are strong supporters of the Foundation Fighting

Blindness. Greg says that their first FFB meeting in Orange County was very encouraging. "After spending time with these people who were professionals, business owners, lawyers, etc., who also happened to be blind, I knew that Lily would be just fine too. She'll get through this," says Greg. "These people couldn't see, but they could do just about everything else."

In 2007 and 2008, the Gaboras raised money for retinal research by getting involved in FFB's Orange County VisionWalk. "I feel like I need to be proactive and do anything I can to help my daughter," says Kristine. "Supporting the research is one thing I can do. FFB's efforts, like the gene therapy trials for LCA, give us great hope for Lily's future. Lily does see... with her ears and hands, but we hope that someday Lily will see with her eyes, as well."

And even young Lily is excited about FFB's efforts. She came with her family and friends to the 2008 Orange County VisionWalk. Kristine recalls, "When we started the walk, Lily asked, 'Mommy, why are we walking?' I said, 'To find a cure for blindness, honey.' Later that day, when we were putting Lily in her car seat to go home, she asked, 'Mommy, did we find it?' I said, 'Find what, honey?' She said 'Did we find the cure?' I told her, 'We're working on it baby and we'll keep walking until we do!'"

# Unbreakable Bond

UP CLOSE: THE HAJJARS



When Toufic and Linda Hajjar married in 1948, very little was known about Usher syndrome, a devastating genetic condition that caused three of their five children to be born profoundly deaf and progressively lose much of their vision. Virtually nothing was happening in the way of Usher syndrome research at the time. The Foundation Fighting Blindness would not come into existence for another 23 years. But as a close-knit and determined family, the Hajjars did everything they could to help their children live happily and successfully.

At first, the Hajjars knew only that their children — Louise, Michael and Marianne — were deaf; vision problems were not pronounced early on. Linda and Toufic sent the children to a school for the deaf, and helped them religiously with speech, lip reading and language development. Linda recalls, “It was a grueling time, but they were very bright. They got good marks in school and could read lips better than anyone.”

Their eldest child, Louise, had vision challenges early in life, but the family did not know why. As her vision worsened, they took her to see a local ophthalmologist who referred them to a Foundation-funded physician, Dr. Eliot Berson, of the Massachusetts Eye and Ear Infirmary at Harvard Medical School. A world-renowned retinal degenerative disease expert, he ultimately determined that all three children had Usher syndrome.

Susan, one of the two hearing-sighted Hajjar children, says that “becoming blind is often a deaf person’s worst fear. Together, deafness and blindness can cause intense isolation and loneliness.”

Louise remembers the tough challenges she had in high school. “It was difficult for me.

Having hearing and vision loss created problems in school where no teachers, students, or friends used sign language. Even though I was able to still read lips quite well, it was difficult for me to follow

the class material.” In her senior year of high school, Louise had a harder time reading lips and lost friends because of the growing barrier to visual communication.

But the family always remained close with four of the five children working in their retail clothing business, Hajjar’s Big and Tall Men’s Clothing Company, which is in its 48th year of doing business in Boston.

Susan says that “inspiration and desperation” led her to change her focus in graduate school from deaf education to creating needed services for deaf-blind people. With others, she founded the Deaf-Blind Contact Center, Inc. in Boston, which has been providing invaluable services with and for deaf-blind people for over 28 years. Along with Myles Gordon, she co-wrote and co-produced the documentary film, “Touching Lives: Portraits of Deaf-Blind People,” which premiered at Boston’s Museum of Fine Arts in 2003.

The Hajjars have been strong supporters of the Foundation for more than 25 years. They and their extended family have participated in the Shades of Spring Gala in Boston for many years. They also established a charitable gift fund to raise money for Foundation research. The family has much optimism that an emerging treatment will halt or reverse the devastating effects of Usher syndrome. Linda says, “The researchers are doing wonderful work. We have a lot of hope.”



**Standing: Toufic Hajjar, Louise Densmore and Susan Hajjar  
Seated: Linda and Michael Hajjar**





# Visionary Pioneer

UP CLOSE: EBBY HALLIDAY ACERS

Say the name “Ebby” in Dallas and everyone knows you are talking about the “first lady” of real estate in Texas, [Ebby Halliday Acers](#). At 97, Ebby Halliday Acers is still the active and beloved Chairman of the Board of Ebby Halliday Realtors, the company she founded in 1945, and which is now one of the largest and best-known privately owned residential real estate firms in the country.

Ebby was an entrepreneur before the word ever became popular and at a time when very few women could compete in a male-dominated business world. Growing up on a farm near Abilene, Kansas, she left home at age 21 to work at the hat counter in a Kansas City department store and soon relocated to head up a department at a store in Dallas. “When I got off the train and saw Dallas sprawled out before me, I thought I had died and gone to heaven,” says Ebby. “I knew Dallas was the place for me.” A few years later, with money she had saved and wisely invested, she opened her own boutique. She got into the real estate business when a customer’s husband issued her a challenge. He was a developer who had built a number of unattractive concrete and steel houses north of Dallas that weren’t selling. “He told me that if I could sell all those crazy hats to his wife, maybe I could sell his crazy houses,” she said.

Ebby went right to work decorating the homes with carpet, cheery wallpaper, and cottage curtains – basically creating the innovative concept of a “model home” or what Realtors now also call “staging.” Within a year, she sold all of the properties. Then she opened her very first office and the rest, as they say, is history. Ebby Halliday Realtors now boasts 30 branch offices. And while Ebby is well-recognized for her business achievements, she is also renowned for being a true philanthropist—giving back generously with her time and talents to

numerous organizations including the Foundation Fighting Blindness.

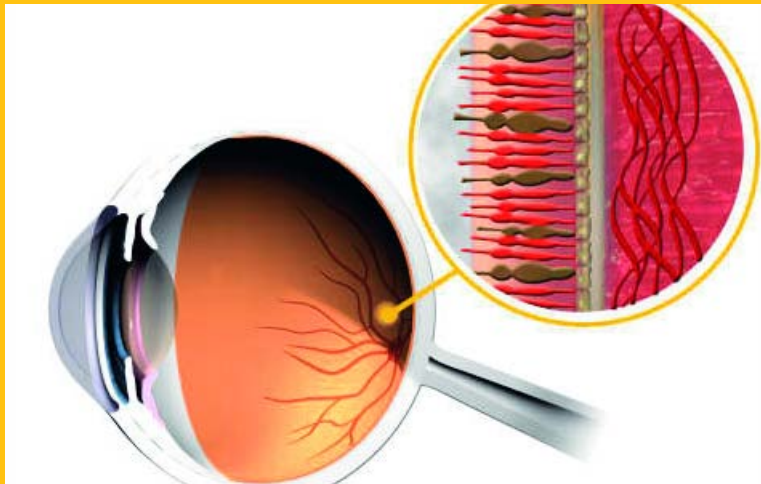
Last year, for all of her philanthropic efforts, FFB honored Ebby in Dallas with its Visionary Award at Dining in the Dark, a unique event where diners eat in complete darkness. Ebby’s friend, T. Boone Pickens, Chairman of BP Capital Management, and Kern Wildenthal, M.D., Ph.D., President of UT Southwestern Medical Center, were also honored at the dinner which raised almost \$400,000 toward research for treatments and cures for retinal diseases.

Ebby is working hard to raise funds for FFB again at the 2009 Dining in the Dark in Dallas, which will honor founder of Perot Systems and Electronic Data Systems, H. Ross Perot, Sr., and entrepreneur Sam Wyly.

Ebby, who has macular degeneration in one eye, was introduced to the work of the Foundation by her “favorite Congressman,” Pete Sessions. Congressman Sessions is a long time supporter of FFB and has a family member affected by retinitis pigmentosa.

“Blindness is so tragic for those children who are born blind or for those young people who are losing their vision,” says Ebby. “Thankfully, the research going on now is amazing. I am hopeful that we will raise a lot of money for the Foundation through this upcoming dinner. Young people are counting on FFB to find a cure. I think the Foundation is doing wonderful work and I am so glad to be working with them.”

# 2008 Research Grants



## FFB CENTER GRANTS

The following 18 FFB-funded Centers foster the collaborative efforts of independent research institutions—pairing basic scientists with clinical investigators—enabling them to better share knowledge and resources to more effectively develop promising treatments and cures.

### **Berman-Gund Laboratory for the Study of Retinal Degenerations**

Harvard Medical School, Massachusetts Eye and Ear Infirmary, Boston, MA

*Eliot L. Berson, M.D., Center Director*

**\$383,604**

*Principal Investigators: Eliot L. Berson, M.D., Tiansen Li, Ph.D., Michael A. Sandberg, Ph.D.*

**Advancing treatments for RP, LCA, AMD, Usher syndrome and other diseases. Identifying disease-causing genes, improving clinical prediction of disease progression, and conducting clinical trials.**

### **The Children's Hospital of Philadelphia (CHOP) –Penn Pediatric Center for Retinal Degenerations**

University of Pennsylvania, Philadelphia, PA

*Jean Bennett, M.D., Ph.D., Center Director*

**\$251,607**

*Principal Investigators: Jean Bennett, M.D., Ph.D., Eric A. Pierce, M.D., Ph.D., Edward N. Pugh, Jr., M.D., Ph.D.*

**Conducting a gene therapy clinical trial for adults and children with LCA (RPE65 gene). Establishing pediatric clinical standards for medical and surgical interventions. Evaluating new treatments in animal models for potential clinical studies.**

### **The Cleveland Clinic Foundation Research Center for the Study of Retinal Degenerative Diseases**

Cole Eye Institute, Cleveland, OH

*Joe G. Hollyfield, Ph.D., Center Director*

**\$243,922**

*Principal Investigators: John W. Crabb, Ph.D., Stephanie A. Hagström, Ph.D., Joe G. Hollyfield, Ph.D., Neal Peachey, Ph.D.*

**Studying AMD in humans and animals including new AMD mouse model. Identifying gene and protein changes, as well as environmental causes such as oxidative damage. Will lead to identification of treatment targets for AMD.**



“Thanks to the Foundation’s unwavering commitment to fund the world’s best researchers and most promising science, we have entered a golden era for sight-saving treatments and cures.”

Morton F. Goldberg, M.D.  
Chairman of FFB’s National  
Neurovision Research Institute

**Greater New York Regional Research Center for the Study of Retinal Degenerative Diseases**

New York University School of Medicine, New York, NY; Edward S. Harkness Eye Institute, Columbia University, New York, NY; University of Medicine and Dentistry, New Jersey Medical School, Newark, NJ

*Lucian V. Del Priore, M.D., Ph.D., Ronald E. Carr, M.D., Marco A. Zarbin, M.D., Ph.D., Center Co-Directors*  
**\$506,230**

*Principal Investigators: Rando L. Allikmets, Ph.D., Ronald E. Carr, M.D., Lucian V. Del Priore, M.D., Ph.D., Stephen Goff, Ph.D., Marco A. Zarbin, M.D., Ph.D.*

**Assessing new clinical treatments—gene replacement, neuroprotective, cell-based, and other strategies—for RP, AMD, Stargardt disease, cone dystrophy and other diseases. Identifying new disease-causing genes and their effects on vision.**

**Jules Stein Eye Institute Research Center for the Study of Retinal Degenerative Diseases**

University of California, Los Angeles, CA  
*Dean Bok, Ph.D., Center Director*

**\$375,949**

*Principal Investigators: Dean Bok, Ph.D., Debora Farber, Ph.D., Michael Gorin, M.D., Ph.D., Steven Nusinowitz, Ph.D., Gabriel H. Travis, M.D., Xian-Jie Yang, Ph.D.*

**Testing drug, gene, and nutritional therapies in animal models of Stargardt disease for future study in humans. Clinically and genetically assessing patients.**

**Kearn Family Center for the Study of Retinal Degeneration**

University of California, San Francisco, CA; University of California, Berkeley, San Francisco, CA; Stanford University School of Medicine, Stanford, CA

*Matthew M. LaVail, Ph.D., Center Director*  
**\$478,186**

*Principal Investigators: Michael Danciger, Ph.D., Jacque Duncan, M.D., John G. Flannery, Ph.D., Matthew M. LaVail, Ph.D., Austin Roorda, Ph.D., Douglas Vollrath, M.D., Ph.D.*

**Testing neuroprotective and gene therapies for RP, AMD, Usher syndrome and other retinal degenerative diseases. Searching for genetic causes of these diseases. Expanding clinical assessments and measurements using high resolution retinal imaging.**

**W.K. Kellogg Eye Center for the Study of Retinal Degenerative Diseases**

University of Michigan, Ann Arbor, MI; University of California, San Diego, CA  
*John R. Heckenlively, M.D., Center Director*

**\$508,633**

*Principal Investigators: Radha Ayyagari, Ph.D., John R. Heckenlively, M.D., Hemant Khanna, Ph.D., Debra A. Thompson, Ph.D., David Zacks, M.D., Ph.D.*

**Identifying gene variations and visual-cycle defects. Determining how these changes cause retinal degenerative diseases such as RP (including X-linked RP), LCA, Stargardt disease and AMD. Identifying and testing treatments for future study in humans.**

**The Michael M. Wynn Research Center  
for the Study of Retinal Degeneration**

Moran Eye Center, University of Utah,  
Salt Lake City, UT; Tufts University School of  
Medicine, Boston, MA

*Wolfgang Baehr, Ph.D., Center Director*

**\$237,154**

*Principal Investigators: Wolfgang Baehr, Ph.D.,  
Paul Bernstein, M.D., Ph.D., Rajendra Kumar-Singh,  
Ph.D., Kang Zhang, M.D., Ph.D.*

**Evaluating drug, gene, and nutritional therapies  
for vision rescue. Identifying disease-causing  
genes in animal models of RP, AMD, LCA,  
cone and cone-rod dystrophies, congenital  
stationary night blindness, and other retinal  
degenerative diseases.**

**Oregon Health & Science University  
Research Center for the Study of  
Retinal Degenerative Diseases**

Casey Eye Institute, Portland, OR; University of  
Florida, Gainesville, FL

*Richard G. Weleber, M.D., Center Director*

**\$527,884**

*Principal Investigators: Peter J. Francis, M.D.,  
Ph.D., William W. Hauswirth, Ph.D., Raymond D.  
Lund, Ph.D., Martha Neuringer, Ph.D.,  
Richard G. Weleber, M.D.*

**Evaluating cell-based, nutritional, and gene  
therapies in human studies and animal models  
of RP. Refining clinical diagnoses and  
correlating them with genetic variations.**

**Paris Research Center for the Study  
of Retinal Degenerative Diseases**

INSERM, Hôpital Saint-Antoine, Hôpital des  
Quinze-Vingts, UCL, Paris, France

*José-Alain Sahel, M.D., Center Director*

**\$286,410**

*Principal Investigators: Thierry Léveillard, Ph.D.,  
Christine Petit, M.D., Ph.D., Saddek Mohand-Said,  
M.D., Ph.D., José-Alain Sahel, M.D.*

**Creating and testing new methods for cone  
rescue in retinal degenerative disease.  
Investigating the causes of Usher syndrome  
type I. Developing techniques to define the  
structure and function of the retina during the  
progression of retinal degenerative diseases.  
Clinically and genetically assessing patients,  
and conducting clinical trials.**

**Pre-Clinical Medical Therapy Evaluation Center**

Cornell University, Ithaca, NY; University of  
Pennsylvania, Philadelphia, PA

*Gustavo Aguirre, V.M.D., Ph.D., Center Director*

**\$485,611**

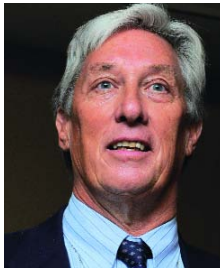
*Principal Investigators: Gregory M. Acland, B.V.Sc.,  
Gustavo Aguirre, V.M.D., Ph.D.,  
Barbara Zangerl, D.V.M., Ph.D.*

**Identifying new disease-causing genes in  
canine models. Researching how variations in  
these genes cause retinal diseases such as: RP,  
Best disease, and achromatopsia. Perfecting  
gene and neuroprotective therapies for future  
use in human studies.**

“The Foundation is providing  
me with invaluable resources  
and support that are enabling  
me to focus my career on  
bringing an end to blinding  
retinal degenerative diseases.”

Jacque Duncan, M.D.  
Clinician and Researcher,  
University of California, San Francisco





“Due in large part to the support from FFB, we have been able to help hundreds of patients in the region, and we have become a highly desirable site for innovative therapeutic approaches for preventing future vision loss and restoring vision.”

David Birch, Ph.D., Retina Foundation of the Southwest

**Research Center for Macular Degeneration and Allied Retinal Disorders**

University of Iowa, College of Medicine, Iowa City, IA  
*Edwin M. Stone, M.D., Ph.D., Center Director*  
**\$506,153**

*Principal Investigators: Terry A. Braun, Ph.D., Todd E. Scheetz, Ph.D., Val Sheffield, M.D., Ph.D., Edwin M. Stone, M.D., Ph.D.*

**Correlating gene variations with clinical symptoms for a wide range of retinal diseases. Collecting this information to more rapidly bring treatments to clinical trials. Developing new techniques and technologies for finding disease-causing genes. Developing a gene therapy for Bardet-Biedl syndrome.**

**Research Center for the Study of Retinal Degenerative Diseases at the Institute of Ophthalmology and Moorfields Eye Hospital**

Institute of Ophthalmology, University College London, London, England, United Kingdom  
*Frederick W. Fitzke, Ph.D., Center Director*  
**\$340,448**

*Principal Investigators: Shomi Bhattacharya, Ph.D., Alan Bird, M.D., Frederick W. Fitzke, Ph.D., Graham E. Holder, Ph.D., Tony Moore, M.D., José-Alain Sahel, M.D., Andrew Webster, M.D.*

**Evaluating participants in a clinical study of gene therapy for LCA. Improving retinal imaging techniques for better clinical monitoring and management of disease progression. Identifying disease-causing genes and correlating variations with clinical symptoms in humans and animals with RP, AMD, LCA, Stargardt disease, and other diseases. Will lead to better treatment targets.**

**Scandinavian Center for the Studies on Hereditary Retinal Diseases**

Wallenberg Retina Center, University Hospital of Lund, Lund, Sweden  
*Theo van Veen, Ph.D., Center Director*  
**\$238,706**

*Principal Investigators: Sten Andréasson, M.D., Ph.D., Theo van Veen, Ph.D.*

**Identifying genetic variations and clinical correlations in humans, and compiling this information into a database to support future clinical studies. Testing neuroprotective treatments in animal models of various diseases.**

**Scheie Eye Institute Retinal Degeneration Research Center**

University of Pennsylvania, Philadelphia, PA; University of Florida College of Medicine, Gainesville, FL; School of Medicine, Case Western Reserve University, Cleveland, OH; Cornell University, Ithaca, NY  
*Samuel G. Jacobson, M.D., Ph.D., Center Director*  
**\$348,966**

*Principal Investigators: Gustavo Aguirre, V.M.D., Ph.D., Artur V. Cideciyan, Ph.D., William W. Hauswirth, Ph.D., Samuel G. Jacobson, M.D., Ph.D., Krzysztof Palczewski, Ph.D.*

**Developing gene therapy treatments for dominant Stargardt disease and LCA. Developing new ways to measure disease progression and provide reliable measurements of success in human clinical trials. Generating new compounds that could be useful for treating retinal degenerations.**

**Southwest Regional Research Center for the Study of Retinal Degenerative Diseases**

Retina Foundation of the Southwest, Dallas, TX; The University of Oklahoma Health Sciences Center, Oklahoma City, OK; The University of Texas Health Science Center at Houston, TX; Mayo Clinic, Rochester, MN

*Robert E. Anderson, M.D., Ph.D., David G. Birch, Ph.D., Center Co-Directors*

**\$596,515**

*Principal Investigators: Muayyad R. Al-Ubaidi, Ph.D., Robert E. Anderson, M.D., Ph.D., David G. Birch, Ph.D., Stephen P. Daiger, Ph.D., Albert O. Edwards, M.D., Ph.D., James F. McGinnis, Ph.D., Muna Naash, Ph.D., Dianna K.H. Wheaton, M.S.*

**Conducting several promising clinical trials. Identifying disease-causing genes, improving clinical detection and diagnoses, testing nanotechnology delivery systems, and evaluating nutritional and gene therapies in animals and humans for RP, AMD, LCA, Stargardt disease, Usher syndrome, and other conditions.**

**University of Illinois at Chicago Research Center for the Study of Retinal Degenerative Diseases**

University of Illinois at Chicago Eye Center, Chicago, IL

*Gerald A. Fishman, M.D., Center Director*

**\$175,774**

*Principal Investigator: Gerald A. Fishman, M.D.*

**Correlating gene variations with clinical symptoms, developing better diagnostic methods, and improving technology for diagnosis and treatment of humans affected by all retinal degenerative diseases. Conducting clinical trials.**



“We have known and trusted the Foundation for more than 30 years. We have attended several VISIONS conferences, and never ceased to be amazed at the tremendous progress being made by Foundation-funded scientists.”

Robert Reintsma, FFB’s Legacy Society

**Wilmer Eye Institute Research Center for the Study of Retinal Degenerative Diseases**

The Johns Hopkins University, Baltimore, MD

*Peter A. Campochiaro, M.D., Center Director*

**\$475,747**

*Principal Investigators: Ruben Adler, M.D., Peter A. Campochiaro, M.D., Nicholas Katsanis, Ph.D., Nicholas Marsh-Armstrong, Ph.D., Jeremy Nathans, M.D., Ph.D., Solomon H. Snyder, M.D., Jennifer U. Sung, M.D., Donald J. Zack, M.D., Ph.D.*

**Studying gene variations causing RP, AMD, and other retinal degenerative diseases. Testing gene and neuroprotective therapies and other drugs in animal models and humans.**

**RESEARCH FACILITIES**

**Joe G. Hollyfield, Ph.D.**

**Cole Eye Institute, Cleveland, OH**

Collecting eye donor tissues for RP, AMD and other diseases. Archiving tissues for access by researchers to understand how disease progresses to find treatments and cures.

**\$75,000**

**John R. Heckenlively, M.D.**

**W.K. Kellogg Eye Center, University of Michigan, Ann Arbor, MI**

Characterizing clinical and genetic aspects of X-Linked RP and AMD. Developing resources for clinical trials of treatments.

**\$91,980**

## CAREER DEVELOPMENT AWARDS

Career Development Awards support talented and ambitious clinician-scientists who are entering the field of retinal disease research. Clinician-scientists are critical to the advancement of retinal research because they are uniquely qualified to conduct clinical trials, they provide critical patient care, and they are strongly committed to the development of innovative treatments and cures.

**Peter Francis, M.D., Ph.D.**

**Oregon Health & Science University, Portland, OR**

Investigating gene therapy and other treatments for a variety of retinal diseases.

**\$68,898**

**Sandeep Grover, M.D.**

**University of Florida Shands Hospital,  
Jacksonville, FL**

Utilizing various electrophysiological tests to better understand and diagnose retinal disease.

**\$68,958**

**J. Jill Hopkins, M.D.**

**Retina-Vitreous Associates, Los Angeles, CA**

Providing clinical care and treatment for retinal diseases.

**\$96,278**

**Stephen H. Tsang, M.D., Ph.D.**

**Edward S. Harkness Eye Institute, Columbia  
University Medical Center, New York, NY**

Developing a stem cell therapy for early-onset retinal dystrophy.

**\$65,000**

## MARJORIE C. ADAMS WOMEN'S CAREER DEVELOPMENT AWARD

**Jacque L. Duncan, M.D.**

**UCSF Department of Ophthalmology,  
San Francisco, CA**

Conducting clinical research for a wide range of retinal diseases.

**\$68,959**

## INDIVIDUAL INVESTIGATOR AWARDS

### CELL-BASED THERAPY

**David M. Gamm, M.D., Ph.D.,**

**James Thomson, Ph.D.,**

**Eric Pierce, M.D., Ph.D.,**

**Ray Lund, Ph.D.,**

**Derek Hei, Ph.D.**

**Waisman Center, University of Wisconsin,  
Madison, WI**

Developing stem cell therapy (induced pluripotent) for recessive retinal degenerative disease.

**Translational Research Acceleration Program**

**\$500,000**

**Hemant Khanna, Ph.D.,**

**David Zacks, M.D., Ph.D.,**

**Jingyu Yao, M.D.**

**W.K. Kellogg Eye Center, University of Michigan,  
Ann Arbor, MI**

Investigating cell transplantation treatment for X-linked RP.

**\$36,977**

**Thomas A. Reh, Ph.D.**

**University of Washington, Seattle, WA**

Investigating development of retinal cells from human embryonic stem cells for transplantation treatments.

**Translational Research Acceleration Program**

**\$88,327**

**Thomas A. Reh, Ph.D.**

**University of Washington, Seattle, WA**

Studying human embryonic stem cell transplantation in animal models.

**\$319,622**

**Michael J. Young, Ph.D.**

**The Schepens Eye Research Institute, Harvard  
Medical School, Boston, MA**

Investigating strategies for using stem cells in retinal transplantation including the development of biodegradable materials to facilitate integration.

**\$105,792**

**Marco Zarbin, M.D., Ph.D.**

**University of Medicine and Dentistry of New Jersey,  
New Jersey Medical School, Newark, NJ**

Investigating human embryonic stem cell lines for retinal pigment epithelial cell transplantation therapies for AMD.

**\$104,833**

## **CELLULAR AND MOLECULAR MECHANISMS OF DISEASE**

**Catherine Bowes Rickman, Ph.D.**

**Duke University Medical School, Durham, NC**

Identifying how variations in the gene Complement Factor H lead to AMD. Will help identify targets for AMD treatments.

**\$98,300**

**Anne L. Calof, Ph.D.**

**University of California, Irvine, CA**

Investigating how factors called GDF-11 and FST may be used to stimulate the retina to grow new cells and halt vision loss from retinal diseases.

**\$101,525**

**Shiming Chen, Ph.D.**

**Washington University, St. Louis, MO**

Evaluating pharmacological treatments in mouse model (caused by variations in Crx gene). Will benefit people with LCA, cone-rod dystrophy, and RP.

**\$100,000**

**Albert O. Edwards, M.D., Ph.D.**

**Mayo Clinic, Rochester, MN**

Evaluating different biomarkers, which can be used to predict a person's risk for AMD.

**\$103,000**

**John R. Heckenlively, M.D.,**

**Naheed Khan, Ph.D.**

**W.K. Kellogg Eye Center, University of Michigan,  
Ann Arbor, MI**

Investigating therapies for X-linked RP.

**\$29,356**

**Janis Lem, Ph.D.**

**Tufts University-New England Medical Center,  
Boston, MA**

Investigating how variations in the rhodopsin gene lead to photoreceptor death in certain forms of RP. Will provide targets for treatments.

**\$91,360**

**Patsy Nishina, Ph.D.**

**The Jackson Laboratory, Bar Harbor, ME**

Identifying new mouse models to pinpoint and test treatment strategies for AMD.

**\$106,090**

**Bjorn R. Olsen, Ph.D.,**

**Alexander Maneros, M.D., Ph.D.**

**Harvard School of Dental Medicine, Boston, MA**

Investigating the role of VEGF and other proteins in the development of wet AMD. May provide new strategies for preventing the death of RPE cells.

**\$106,061**

**Eric A. Pierce, M.D., Ph.D.**

**Scheie Eye Institute, University of Pennsylvania  
School of Medicine, Philadelphia, PA**

Investigating mouse models of RP caused by variations in RP1 gene, and evaluating a drug for correcting the genetic transcription process that leads to vision loss.

**\$90,093**

**Hui Sun, Ph.D.**

**UCLA School of Medicine, Los Angeles, CA**

Investigating how the gene CFH leads to the development of drusen and AMD. May lead to better ways to treat and prevent AMD.

**\$87,785**

## **GENE THERAPY**

**Jean Bennett, M.D., Ph.D.,**

**Arkady Lyubarsky, Ph.D.,**

**Thierry Léveillard, Ph.D.,**

**José-Alain Sahel, M.D.**

**University of Pennsylvania, Philadelphia, PA**

Researching gene delivery of Rod-Derived Cone Viability Factor, which shows great promise in preventing vision loss from RP and other conditions.

**\$100,002**

“FFB is ensuring that we bring together the brightest minds to deliver lasting and real cures for everyone affected by retinal diseases.”

Congressman Pete Sessions



**Jean Bennett, M.D., Ph.D.,**  
**Alberto Auricchio, M.D.,**  
**Sha Li, M.D.,**  
**Albert Maguire, M.D.,**  
**Defne Amado**  
**University of Pennsylvania, Philadelphia, PA**  
Investigating gene therapy for X-linked RP caused by variations in the gene RPGR.  
\$74,269

**Eliot L. Berson, M.D.,**  
**Tiansen Li, Ph.D.**  
**Berman-Gund Laboratory, Harvard Medical School, Massachusetts Eye and Ear Infirmary, Boston, MA**  
Investigating gene therapy for LCA due to variations in the gene RPGRIP.  
\$76,200

**Peter A. Campochiaro, M.D.**  
**Wilmer Eye Institute, The Johns Hopkins University School of Medicine, Baltimore, MD**  
Investigating gene therapy in animal models of AMD.  
\$50,000

**William W. Hauswirth, Ph.D.**  
**University of Florida College of Medicine, Gainesville, FL**  
Developing gene therapy to preserve cone function in X-linked RP caused by variations in the gene RPGR.  
\$76,474

**Alfred S. Lewin, Ph.D.,**  
**Marina Gorbatyuk, Ph.D.**  
**University of Florida College of Medicine, Gainesville, FL**  
Developing gene therapy for treatment of autosomal dominant RP.  
\$102,573

**Tiansen Li, Ph.D.**  
**Massachusetts Eye and Ear Infirmary, Harvard University, Boston, MA**  
Exploring gene replacement therapy approaches in animal models of retinal degeneration.  
\$87,937

**Miguel Seabra, M.D., Ph.D.,**  
**Tanya Tolmochova**  
**Imperial College of Science, London, England**  
Developing a gene replacement therapy for a mouse model of choroideremia.  
\$79,401

**Debra A. Thompson, Ph.D.**  
**W.K. Kellogg Eye Center, University of Michigan, Ann Arbor, MI**  
Investigating small-molecule therapies for X-linked RP.  
\$32,924

**Barbara Zangerl, V.M.D., Ph.D.**  
**University of Pennsylvania, School of Veterinary Medicine, Philadelphia, PA**  
Studying dog models of Best disease to better understand the disease and test therapies.  
\$120,000

## GENETICS

**Nicolas G. Bazan, M.D., Ph.D.,**

**William Gordon, Ph.D.**

**Louisiana State University Health Sciences  
Center, New Orleans, LA**

Developing a mouse model for Usher 1C to be used as a tool for testing potential treatments.

**\$102,911**

**Stephen P. Daiger, Ph.D.,**

**Sara J. Browne, Ph.D.,**

**Lori S. Sullivan, Ph.D.**

**University of Texas Health Science  
Center at Houston, TX**

Determining which forms of RP and other related diseases are caused by a type of genetic variation known as a large deletion. Will help identify treatment targets.

**\$80,894**

**Stephen P. Daiger, Ph.D.,**

**Sara J. Browne, Ph.D.,**

**Lori S. Sullivan, Ph.D.**

**University of Texas Health Science Center at  
Houston, TX**

Searching for genes that cause RP using advanced screening technology.

**\$250,000**



**Anneke I. den Hollander, Ph.D.**

**Radboud University, Nijmegen Medical Centre,  
Nijmegen, The Netherlands**

Utilizing a new technique called “ophthalmogenomics” to uncover disease-causing genetic variations in people with LCA and recessive forms of RP.

**\$79,972**

**Akihiro Ikeda, Ph.D.**

**University of Wisconsin - Madison, WI**

Evaluating a mouse model of retinoschisis to better understand the mechanisms of vision loss in the disease. Will provide better targets for treatments.

**\$31,300**

**Josseline Kaplan, M.D., Ph.D.,**

**Jean-Michel Rozet, Ph.D.,**

**Isabelle Perrault, Ph.D.,**

**Sylvain Hanein, Ph.D.,**

**Sylvie Gerber, Engineer,**

**Nathalie Delphin, Engineer**

**INSERM U393 - Hôpital des Enfants Malades,  
Paris, France**

Working with a mouse model of LCA (caused by variations in the gene GUCY2D) to better understand disease mechanisms. Identifying individuals with changes in many of the genes that cause LCA. Will lay groundwork for future LCA clinical studies.

**\$55,539**

**William J. Kimberling, Ph.D.**

**Boys Town National Research Hospital, Omaha, NE**

Building infrastructure for genetic and epidemiologic studies of Usher syndrome to improve diagnosis and facilitate future clinical trials.

**\$43,609**

“More has been learned in the past 20 years about the causes of retinal diseases, and about possible cures, than in all of the years before. The Foundation Fighting Blindness has been the major driving force behind this explosion of knowledge. And the next 10 years will be even better, thanks to FFB!”

Stephen P. Daiger, Ph.D., University of Texas Health Science Center at Houston

**Dror Sharon, Ph.D.**  
**Hadassah-Hebrew University Medical Center,**  
**Jerusalem, Israel**

Identifying new genes causing a variety of inherited retinal degenerations.

**\$100,000**

**Edwin M. Stone, M.D., Ph.D.,**  
**Todd E. Scheetz, Ph.D.,**  
**Val Sheffield, M.D., Ph.D.,**  
**Thomas L. Casavant, Ph.D.**

**University of Iowa, Iowa City, IA**

Screen large samples of human DNA to identify new genetic variations that cause autosomal recessive RP.

**Translational Research Acceleration Program**

**\$250,025**

### **NEUROPROTECTIVE THERAPY**

**William A. Beltran, D.V.M., Ph.D.**  
**University of Pennsylvania, Philadelphia, PA**

Optimizing the effect of ciliary neurotrophic factor (CNTF) for treating RP.

**\$65,206**

**Jeffrey H. Boatright, Ph.D.,**  
**John M. Nickerson, Ph.D.**  
**Emory University Eye Center, Emory University**  
**School of Medicine, Atlanta, GA**

Researching the overall effects of a synthetic gallbladder bile acid, TUDCA, in animal models of retinal degeneration.

**\$102,970**

**Michael E. Boulton, Ph.D.,**  
**Massoud Motamedi, Ph.D.**  
**University of Texas Medical Branch, Galveston, TX**

Investigating use of nanomedicine to remove lipofuscin – toxic deposits linked to retinal conditions such as dry AMD, Stargardt disease, and Best disease.

**\$98,961**

**Wei Cao, Ph.D.**  
**University of Oklahoma Health Sciences Center,**  
**Oklahoma City, OK**

Investigating neuroprotective agents as therapies for Usher syndrome type 1.

**\$36,885**

**Rosalie K. Crouch, Ph.D.,**  
**Bärbel Rohrer, Ph.D.,**  
**John Oatis**

**Medical University of South Carolina, Charleston, SC**

Developing a pharmacological agent to keep cones functional in patients with LCA involving RPE65 mutations.

**\$77,965**

**Janis T. Eells, Ph.D.**  
**University of Wisconsin, Milwaukee, WI**

Investigating near-infrared radiation for retinal repair.

**\$42,500**

**Matthew M. LaVail, Ph.D.**  
**Beckman Vision Center, UCSF School of**  
**Medicine, San Francisco, CA**

Investigating various neuroprotective and combinational therapies for retinal degenerations.

**Translational Research Acceleration Program**

**\$150,000**

**Thierry Léveillard, Ph.D.,**  
**José-Alain Sahel, M.D.**  
**Institute de la Vision-INSERM, Paris, France**

Identifying plant extracts that can be used to protect cone cells in the retina.

**Translational Research Acceleration Program**

**\$312,021**

**James F. McGinnis, Ph.D.**  
**University of Oklahoma Health Sciences Center,**  
**Oklahoma City, OK**

Investigating neuroprotective agents as therapies for Usher syndrome type 1.

**\$61,389**

**Bärbel Rohrer, Ph.D.,**  
**Craig Beeson, Ph.D.**  
**Medical University of South Carolina, Charleston, SC**

Utilizing advanced screening techniques to identify anti-degenerative agents in the retina.

**Translational Research Acceleration Program**

**\$200,000**

**Bärbel Rohrer, Ph.D.**

**Medical University of South Carolina, Charleston, SC**

Examining the therapeutic benefit of blocking the inflammatory pathway that leads to AMD. Providing a target for development of AMD prevention.

**\$100,000**

**Marius Ueffing, Ph.D.,**

**Stefanie M. Hauck, Ph.D.**

**Institute of Human Genetics, GSF-National Research Center, Neuherberg, Germany**

Evaluating the vision-protecting qualities of proteins produced by cells in the retina. Proteins may preserve vision in people with RP and other conditions.

**\$103,000**

**Donald J. Zack, M.D., Ph.D.**

**Wilmer Eye Institute, Johns Hopkins University School of Medicine, Baltimore, MD**

Identifying new neuroprotective factors that prevent photoreceptor degeneration and vision loss for RP and other conditions.

**\$103,000**

**Donald J. Zack, M.D., Ph.D.,**

**Hongjun Song, Ph.D.**

**Wilmer Eye Institute, The Johns Hopkins University School of Medicine, Baltimore, MD**

Screening small molecules that promote retinal cell survival.

**Translational Research Acceleration Program**  
**\$300,312**

## **NUTRITIONAL/ENVIRONMENTAL THERAPIES**

**Paul S. Bernstein, M.D., Ph.D.,**

**Werner Gellermann, Ph.D.**

**Moran Eye Center, University of Utah, Salt Lake City, UT**

Measuring macular pigment levels in human retinas to better understand the roles of lutein and zeaxanthin in reducing AMD risk.

**\$60,000**

**Johanna M. Seddon, M.D.**

**Harvard University School of Medicine, Boston, MA**

Evaluating the interaction between genetics and nutrition in the risk of developing AMD.

**\$105,030**

## **OTHER FFB FY08 GRANTS AND MEETING/CONFERENCE SUPPORT**

**Robert E. Anderson, M.D., Ph.D.**

**University of Oklahoma Health Sciences Center, Oklahoma City, OK**

XIIIth International Retinal

Degeneration Symposium

September 18 - 23, 2008 at Emmiashan,

Sichuan Province, China

**\$15,000**

**Kate Ahlport**

**Health Research Alliance, Inc.,**

**Research Triangle Park, NC**

2008 HRA National Conference

Accelerating Medical Discovery Through

Strategic Philanthropy

March 4 - 6, 2008 at Washington, D.C.

**\$10,000**

## **FFB AWARDS**

### **BOARD OF DIRECTORS RETINAL DEGENERATION RESEARCH AWARD**

Awarded to Dr. Tiansen Li and Dr. Uwe Wolfrum for their contributions toward defining the role of Usher syndrome proteins in photoreceptor biology, thereby elucidating potential targets for treatments and cures, including gene therapy. The proteins they discovered affect the cilia in the retina and the cochlea of the ear. Cilia are the tiny hairs that act as a critical transportation system in the eye and the ear. Thanks to Drs. Li and Wolfrum, there is great hope for saving the vision of thousands of people in the U.S. and around the world who have certain forms of Usher syndrome.

**Tiansen Li, Ph.D.**

**Massachusetts Eye and Ear Infirmary, Harvard University, Boston, MA**

**\$12,500**

**Uwe Wolfrum, Ph.D.**

**Johannes Gutenberg University of Mainz, Germany**

**\$12,500**

## **NATIONAL NEUROVISION RESEARCH INSTITUTE FY08 GRANTS AWARDED**

### **Clinical Assessment Centers**

**Richard G. Weleber, M.D.**

**Oregon Health & Science University, Portland, OR**

Conducting Phase II/III clinical trials of Encapsulated Cell Technology for delivery of vision-preserving protein CNTF for RP.

**\$183,645**

### **Pre-Clinical Assessment Centers**

**Peter A. Campochiaro, M.D.**

**Wilmer Eye Institute, The Johns Hopkins University School of Medicine, Baltimore, MD**

Evaluating therapeutic agents in mouse models for treatment of AMD.

**\$60,000**

**Theo van Veen, Ph.D.,**

**Per Ekström, Ph.D.**

**Wallenberg Retina Center, University Hospital of Lund, Lund, Sweden**

Screening numerous drugs and agents for potential use as treatments in retinal degenerative diseases.

**\$60,000**

**Rong Wen, M.D., Ph.D.**

**University of Pennsylvania, Philadelphia, PA**

Investigating neurotrophic factors for preserving vision in retinal degeneration.

**\$60,000**

## **NATIONAL NEUROVISION RESEARCH INSTITUTE INDIVIDUAL GRANTS**

### **CELL-BASED THERAPY**

**Weng Tao, M.D., Ph.D., Neurotech USA, Lincoln, RI**

Encapsulated Cell Technology (ECT)-based delivery of anti-angiogenic factors for the treatment of macular edema.

**Translational Research Acceleration Program  
\$500,000**

### **GENE THERAPY**

**Alberto Auricchio, M.D., Francesca Simonelli, M.D.**

**Telethon Institute of Medicine and Genetics (TIGEM), Telethon Foundation, Naples, Italy**

**Jean Bennett, M.D., Ph.D., Albert Maguire, M.D.**

**University of Pennsylvania, Philadelphia, PA**

**Katherine High, M.D., J. Fraser Wright, Ph.D.**

**Center for Cellular and Molecular Therapeutics,**

**The Children's Hospital of Philadelphia,**

**Philadelphia, PA**

Preparing for a Phase I clinical study of gene therapy for Stargardt disease.

**Translational Research Acceleration Program  
\$1,089,227**

**David S. Williams, Ph.D., Jules Stein Eye Institute,**

**University of California, Los Angeles, CA**

**Samuel G. Jacobson, M.D., Ph.D., Artur V.**

**Cideciyan, Ph.D., Tomas S. Aleman, M.D.**

**Scheie Eye Institute, University of Pennsylvania,**

**Philadelphia, PA**

**William Hauswirth, Ph.D., University of Florida**

**College of Medicine, Gainesville, FL**

Developing a gene therapy for people with Usher syndrome 1B.

**Translational Research Acceleration Program  
\$513,920**

### **NEUROPROTECTIVE THERAPY**

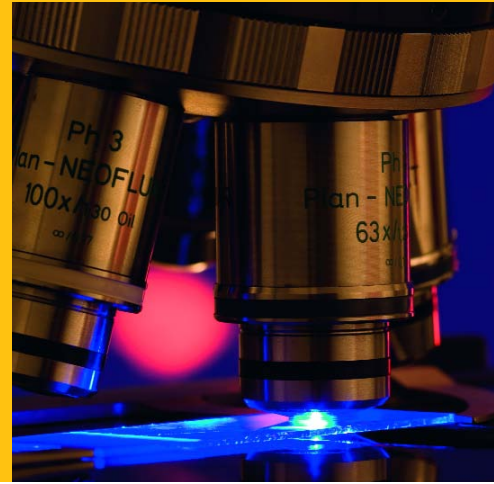
**Steven Pittler, Ph.D., Vision Science Research**

**Center, University of Alabama at Birmingham, AL**

Investigating a neuroprotective drug in animal models of RP.

**\$70,000**

# Advancing Research to Find a Cure



The Foundation Fighting Blindness depends on the generosity of donors to advance sight-saving research. FFB provides a number of ways for people to give including:

## **Gifts**

Cash gifts are a great way to advance FFB's mission. Donate online quickly and securely at [www.FightBlindness.org](http://www.FightBlindness.org) or call 1-800-683-5555. The Foundation also welcomes gifts of stock, personal property, and real estate. Checks can be mailed to: P.O. Box 17279, Baltimore, MD, 21203-7279. Gifts can also be made in tribute to friends and loved ones.

## **Events**

Every year thousands of people participate in FFB fundraising events such as VisionWalk, Dining in the Dark, golf tournaments, wine tastings, and other local fundraising activities. Find events in your area by visiting [www.FightBlindness.org](http://www.FightBlindness.org).

## **Volunteering**

An individual's talents and professional associations can be enormously beneficial to FFB — in both leadership and supporting roles. To learn more about volunteering opportunities in your community, call 1-800-683-5555.

**The Foundation Fighting Blindness is approved by the Office of Personnel Management for participation in the Combined Federal Campaign (#11721).**

**Contributions to the Foundation are tax deductible to the full extent of the law.**



# Planned Giving and FFB's Legacy Society

Naming the Foundation Fighting Blindness in a will or living trust can also be an effective way to provide funding for sight-saving research.

A charitable gift annuity is one of the most secure forms of generating income for you or loved ones while making a gift to FFB. A charitable gift annuity is an agreement by an individual to give a sum of money or property to a charitable organization, and in return, receive a guaranteed fixed income.

The **Legacy Society** is a group of Foundation Fighting Blindness donors who have made a lasting commitment to finding the treatments and cures for retinal degenerative disease by naming the Foundation as a beneficiary of their estate plans. The **Legacy Society** is a way for the Foundation to recognize this profound contribution to retinal research.

We thank **Legacy Society** members for their support, encouragement and commitment to finding a cure!

## Legacy Society Benefits

- **Personalized Certificate of Membership**
- **Invitation to Visionary Council reception at the Visions Conference**
  - **VIP registration and seating at the Visions Conference**
- **Recognition listing in FFB's publications: *InFocus* and *Legacy* (with your permission only)**
  - **Foundation Fighting Blindness Annual Report**
  - **Updates on Foundation research and other news**
- **Invitations to FFB Chapter meetings, symposia and special events**

# A Message from our Treasurer

I am pleased to present the Foundation Fighting Blindness' Statement of Activities and Financial Position. In FY 2008 there was great news to report regarding significant scientific breakthroughs as well as in the number of dollars going to research. Last year, more than \$18 million was spent or earmarked for research. This represents a dramatic increase of 23% or more than the \$3.3 million going to research in the previous year. This means that more dollars than ever were able to go to promising research projects at prominent institutions around the world.

In addition, more than \$2.6 million was spent in FY08 on public health education programs, which help to inform and support those affected by retinal degenerative diseases. This represents an increase of more than 35% over the previous year.

With our revenue at more than \$32.5 million, our Visions 2012 program is right on target. Our goal is to increase total revenue to \$40 million by 2012, and we are well on our way. It is truly an exciting time for retinal disease research and for the Foundation Fighting Blindness and our financial statements are another reflection of our tremendous progress.

Our complete financial statements were audited by Raffa, P.C. independent certified auditors. A complete copy of our audited financial statements is available upon request from the Foundation Fighting Blindness, 11435 Cronhill Drive, Owings Mills, MD 21117, or on our website at [www.FightBlindness.org](http://www.FightBlindness.org).

Sincerely,



**Haynes P. Lea**

*Vice President and Treasurer*

**Statement of Activities**

	<b>2008</b>	<b>2007</b>
<b>Revenue and Support</b>		
Contributions	\$ 20,342,000	\$ 10,719,000
Special events, net of direct	6,534,000	6,773,000
Bequests	4,304,000	2,523,000
Other revenue	1,399,000	1,301,000
<b>Total Revenue</b>	<b>\$ 32,579,000</b>	<b>21,316,000</b>
<b>Expenses</b>		
Research	\$ 18,182,000	14,839,000
Public Health Information	2,640,000	1,939,000
Management	2,130,000	1,696,000
Fundraising	7,784,000	6,805,000
<b>Total Expenses</b>	<b>30,736,000</b>	<b>25,279,000</b>
Change in unrestricted net assets	508,000	(973,000)
Change in restricted net assets	1,335,000	(2,990,000)
<b>Total change in net assets</b>	<b>\$ 1,843,000</b>	<b>\$ (3,963,000)</b>

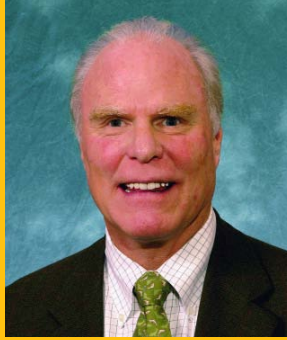
**Statement of Financial Position**

<b>Assets</b>		
Cash and investments	\$ 15,472,000	11,882,000
Pledges receivable, net	7,722,000	6,768,000
Other assets	1,215,000	586,000
Trusts and other funds	5,391,000	4,305,000
Fixed assets, net	1,348,000	1,458,000
<b>Total Assets</b>	<b>\$ 31,148,000</b>	<b>\$ 24,999,000</b>
<b>Liabilities</b>		
Accounts payable and accrued liabilities	\$ 1,484,000	\$ 911,000
Research grants payable	8,840,000	5,350,000
Deferred revenues	285,000	198,000
Liabilities under trusts and other funds	903,000	747,000
<b>Total liabilities</b>	<b>11,512,000</b>	<b>7,206,000</b>
<b>Net Assets</b>		
Unrestricted net assets	\$ 4,475,000	2,817,000
Board designated net assets	3,270,000	4,420,000
Temporarily restricted net assets	11,391,000	10,056,000
Permanently restricted net assets	500,000	500,000
<b>Total net assets</b>	<b>19,636,000</b>	<b>17,793,000</b>
<b>Total liabilities and net assets</b>	<b>\$ 31,148,000</b>	<b>\$ 24,999,000</b>

## LEADERSHIP

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*Chairman*



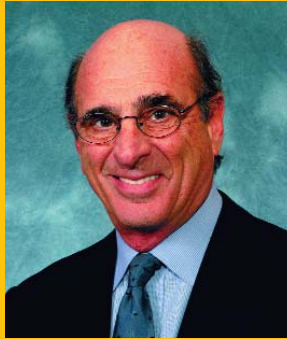
Gordon Gund

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*Vice Chairman*



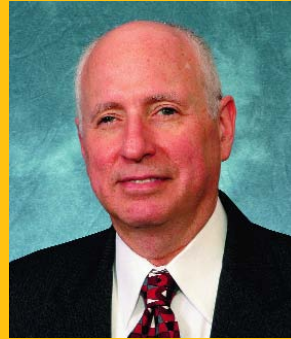
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Edward H. Gollob

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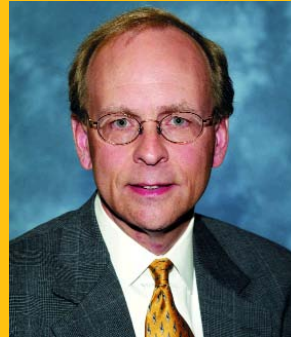
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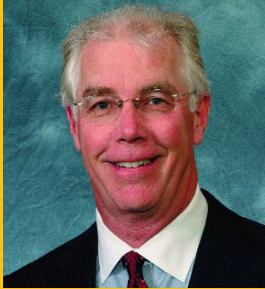
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Michael J. Young, Ph.D.

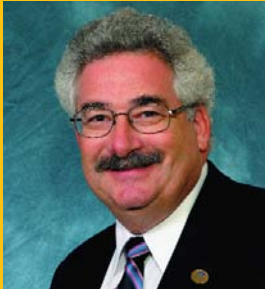
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Stephen M. Rose, Ph.D.



Annette Hinkle, CPA



Patricia A. Dudley

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212-244-1470

**Mid-Atlantic Region**  
410-568-0150

**Southern Region**  
919-781-8014

**Florida Region**  
954-308-5555

**Midwest Region**  
847-680-0100

**Texas Region**  
214-566-9061

**Northern California Region**  
408-739-1846

**Southern California Region**  
310-207-2089

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**Foundation Fighting Blindness**

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410-363-2393 fax

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