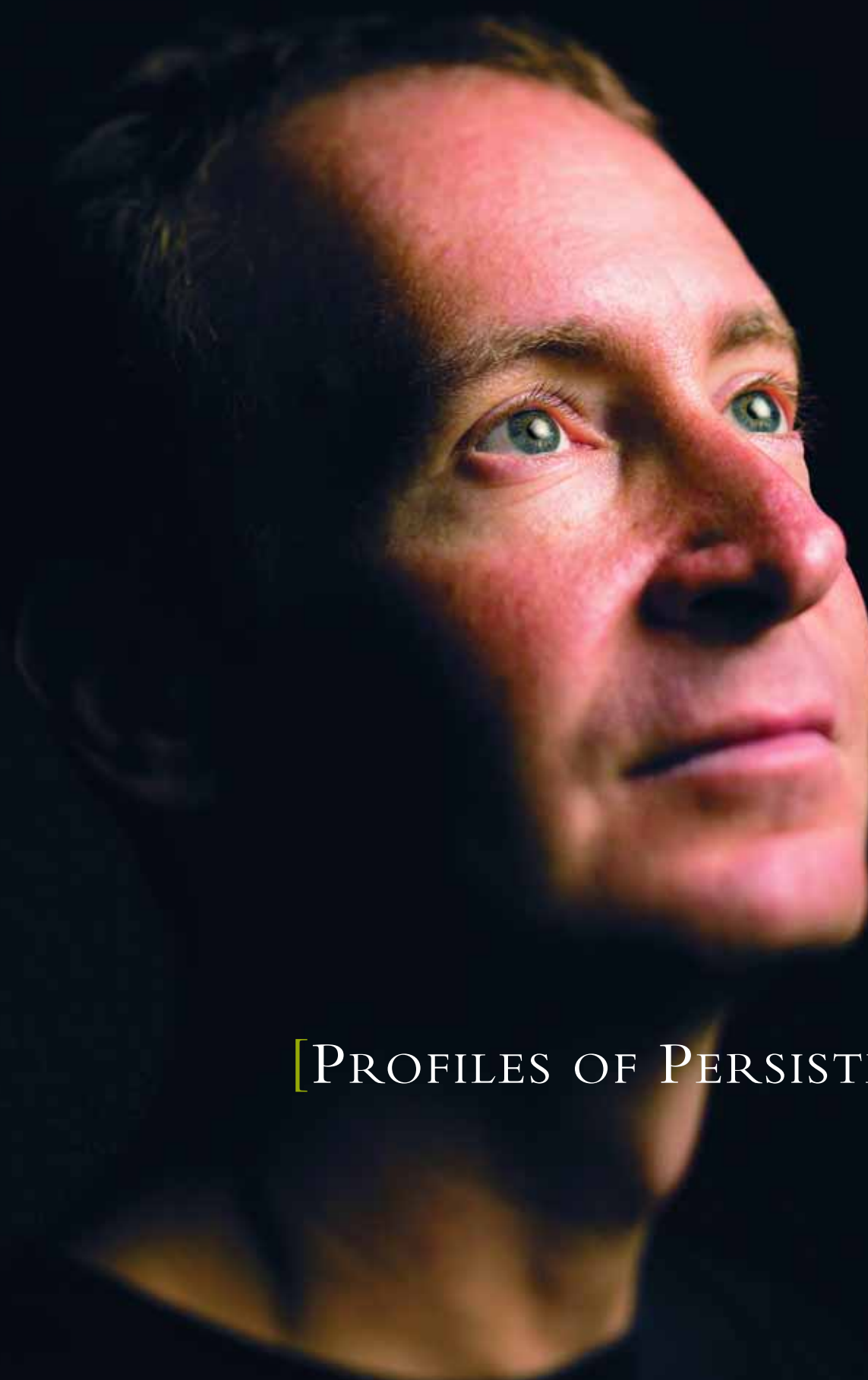


The Foundation Fighting Blindness  
2005 Annual Report



[PROFILES OF PERSISTENCE]

[ Table of Contents ]

1	Mission Statement
2	Message from Chairman and CEO
4	Stories of Persistence
11	Scientific Advances
16	Research Grants
21	National Neurovision Research Institute
22	Financial Report
24	How You Can Help
26	Leadership

ON THE COVER:

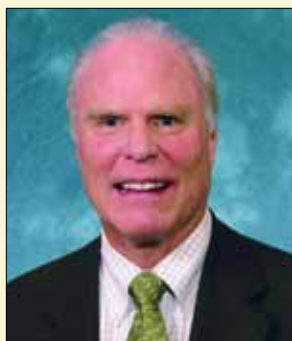
FFB friend and fundraiser Michael Stone,  
as photographed by Erik Stenbakken.

Read Michael's remarkable story on page 4.

The urgent mission of The Foundation Fighting Blindness is to drive the research that will provide preventions, treatments and cures for people affected by retinitis pigmentosa, macular degeneration, Usher syndrome, and the entire spectrum of retinal degenerative diseases.

## [A MESSAGE FROM OUR CHAIRMAN AND OUR CEO]

Spend 10 minutes with anyone from The Foundation Fighting Blindness, and you'll be left with little doubt about our passion and determination to eradicate retinal degenerative diseases. Not unlike the vision-robbing diseases we seek to overcome, our community of donors, researchers, employees, and volunteers is unyielding and persistent. Furthermore, our enthusiasm and doggedness are contagious. They're qualities that account for much of our growth and success, and it is our strength in character that will carry us forward into 2006 and beyond.



Gordon Gund



William T. Schmidt

We encourage you to spend a few minutes learning about a few of our persistent friends, whose stories are featured in this Annual Report. There's Michael Stone, an unstoppable Ironman triathlete with cone-rod dystrophy; the Mack family, whose successful fundraising golf tournaments expand important research opportunities; and Loretta Hoffelder, who lives courageously despite vision loss from age-related macular degeneration.

Over the past 34 years, our growing community of resolute supporters has worked tirelessly to preserve, protect, and restore the vision of people affected by retinal degenerative diseases. Together, through the money we've raised and the breakthroughs those funds have made possible, we get closer to our goals every day. Our unwavering commitment has enabled us to realize enormous advancements—from promising gene therapies to vision-preserving proteins to nutritional supplements—with the first human clinical trials now coming to fruition.

The past year has been exceptionally productive at The Foundation. We established the FFB Stem Cell Research Consortium to pursue therapies that offer promise for people with the

most advanced disease. Currently, FFB is only funding adult stem cell research for potential retinal repair and regeneration treatments. In addition, through our support organization, the National Neurovision Research Institute and its 2004 symposium, we assembled leading experts in research, business, and government to jump-start human clinical trials.

Ironically, with all of our efforts and accomplishments, we are at a point which requires us to be considerably more aggressive and strategic in our development efforts. The reality of forthcoming clinical trials — the fact that they cost exponentially more than laboratory research — places a whole new level of demand for revenue in 2006 and beyond.

The Foundation's leadership has established a blueprint for taking us to a new level of revenue development, and ultimately, through clinical trials, to the reality of effective treatments and cures. The plan includes raising annual revenue from \$16 million to \$40 million by 2012. We'll achieve that goal by increasing our investment in our development infrastructure. This includes substantial expansion of our development field offices, increased corporate and foundation giving, new events, enhanced customer service to our volunteers, and new revenue generation efforts through the Web and other Internet resources.

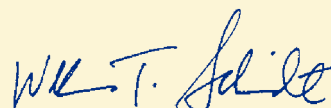
Perhaps the most novel element of our plan is the implementation of a national fundraising walk program, VisionWalk, which we will roll out in five geographical areas in spring 2006, and expand annually thereafter. Not only will the walks boost revenue, they will significantly raise awareness of The Foundation and our mission, ultimately increasing our community of donors, volunteers, and other supporters. Through the investments we're making in development, we will be able to sustain our commitment to this program and make it a success.

The efforts of our volunteers, researchers, leaders, and employees have been nothing short of remarkable during 2005 and our entire 34-year history. Without our strong, unwavering commitment, we wouldn't have the opportunities for treatments and cures that we have today. As we applaud our achievements over the past year, we must keep in mind that 2006 and beyond will demand even more from us. The Foundation's boards of directors and trustees, and senior managers have laid the groundwork for moving many of the promising advancements into vision-restoring treatments and cures. And it will take nothing short of the same passion and persistence to propel us forward.

To all of you who participate in the mission of The Foundation Fighting Blindness, we deeply thank you for your enthusiastic support and hard work. As we move forward together in this exciting period of growth, we are confident that we will triumph over retinal degenerative diseases.



**Gordon Gund**  
*Chairman of the Board*



**William T. Schmidt**  
*Chief Executive Officer*

## [MICHAEL STONE]

Michael Stone lay on the side of the road wincing in pain from a dislocated shoulder and the bleeding “road rash” on his body caused by the fall he took when another cyclist crashed into him.

Michael was competing in a grueling Ironman triathlon which combines a 2.4-mile swim, a 112-mile bike, and a full 26.2-mile marathon. So much of the race was still ahead of him, and between his banged up body and a cracked bike, finishing seemed impossible.

“There comes a race in every athlete’s life when circumstances beyond your control keep you from finishing,” thought Michael as he lay in the near-hundred degree heat. “But this can’t be that day, this race can’t end here—there are people at the finish line counting on me.”

It took Michael a half hour to get himself and his bike together, but eventually he managed. At the end of the day, he crossed the finish line in qualifying time to the cheers of his family, friends and fans from The Foundation Fighting Blindness. The clock told him that this was not his best finish, but he knew in his heart that this race was by far his best effort.

Michael Stone knows a thing or two about persistence. All of his life he has lived with “poor eyesight”—struggling to see the blackboard in school and falling behind his classmates. Unsympathetic teachers wrote him off because they didn’t understand his vision problem. Nevertheless, Michael pushed himself through college and went on to a very successful career as a hotel developer and real estate entrepreneur.

Since he was a little boy, visits to the ophthalmologist were commonplace. Doctor after doctor could not explain his failing eyesight. Finally, just two years ago, at age 35, Michael, who lives in Boulder, Colorado, visited Foundation-funded researcher and clinician Dr. Gerald Fishman at the University of Chicago. Dr. Fishman diagnosed Michael with CONE-ROD DYSTROPHY, an inherited retinal disease that is slowly stealing his vision and which currently has no cure.

Michael was stunned by the news and questioned how so many doctors were unable to identify his problem. While he still has a hard time adjusting to the prospect of losing his eyesight, Michael is not someone who spends a lot of time focusing on the negatives.

“I’m not going to sit here and wait until someone else finds a cure,” says Michael. “I’m going to live my life to the fullest and at the same time, I’m going to work to help solve this. I want to do my part to make the future a little brighter for all of those kids out there who live with the prospect of going blind.”

In his quest for answers about his disease, Michael soon found The Foundation Fighting Blindness. “The people at FFB really got me excited about all of the research going on,” says Michael. “Thanks to FFB and its staff members, I really feel like I have someone in my corner.”

Michael regularly encourages other athletes to raise money for charity while competing in events, and has personally raised money for various causes in the past. Recently, he chose FFB to be the recipient of his fundraising initiatives for that fateful Ironman competition that left him physically bruised and broken, but emotionally charged. Michael raised an impressive \$30,000 through this one event alone.

“Persistence is never quitting, never settling and never accepting failure as an option. I truly believe that with persistence, we will find a cure. I know it’s no longer a question of *if* we will find a cure, but *when*.”



Foundation  
Fighting Blindness

orca

breath4cf





## [THE MACK FAMILY]

It's another "typical" evening at the Mack house. After a full day's work, mom is racing off to bring Andy his cleats for football practice. Dad is picking up Bobby at school, dropping him off at basketball and then heading to a scout meeting with Danny. Somehow, they will make sure everyone gets their homework done, prepare a healthy dinner, and plan for the next hectic day with their bright and energetic boys.

Like most parents, Steve and Lisa want to make sure that their sons get the most out of their school years and help them plan for their future. But they also know that for two of their three sons, these years may have special significance. That's because their youngest boys, Bobby, 10, and Danny, 8, are slowly losing their eyesight to RETINITIS PIGMENTOSA.

"Doctors can't pinpoint exactly when the boys will lose their vision," says Steve, his voice cracking with emotion as his eyes well with tears. "It could be months or years—we just don't know."

The boys currently have trouble with their peripheral vision and suffer from night blindness. "Events like Halloween are particularly stressful. Trick-or-treating, even in familiar surroundings, is very difficult," says Lisa. "It's very embarrassing for Bobby and Danny when we have to guide them by the hand. They don't understand how the other kids, including their older brother, can see to race ahead. It tears us apart inside as we watch them struggle."

Steve and Lisa have not yet shared the news with Bobby and Danny, but finally told older brother Andy, 12, who cried when he learned the news and immediately became very protective of his siblings.

For now, the Macks want their children to have as normal of a childhood as possible and work hard to provide them with visual memories that may have to last a lifetime. "They are such happy little boys, and I don't want them to have this worry hanging over their heads," says Lisa. "But I know we'll have to tell them soon—to help them plan for their future—and it pains me to think about that day."

When Steve and Lisa first learned that the boys had RP, they compared it to mourning a death. But they drew inspiration from their faith, from each other, their families, and from people like Gordon Gund, The Foundation Fighting Blindness' co-founder and Chairman of the Board. "Gordon has accomplished so much in his life," says Steve, "He gave us hope that our boys could lead successful, fulfilling lives with or without vision."

Though the Macks are hopeful, they're doing as much as possible to put the future in their own hands. Five years ago Steve and Lisa set out to raise money to find a cure for blindness through their Swing for Sight golf tournament in Maryland. To date, the event has raised more than \$500,000 for The Foundation Fighting Blindness.

"I feel confident that there is a cure out there for my children. There is a lot of exciting research taking place and that helps us to stay optimistic about our children's future. We have hope, and that's something we can hang onto." —Lisa Mack

## [LORETTA HOFFELDER]

It was 1980 and Loretta Hoffelder was busy running her own business, Semrow Office Service, and enjoying a very active social life due in part to the years her husband served as an Illinois State Senator and Representative.

“One morning, all of a sudden,” said Loretta, “the lines on the newspaper got wavy. After adjusting the newspaper and the lighting, I thought to myself, I must need new glasses.”

But a trip to the ophthalmologist revealed something far more serious. Loretta was shocked to learn that she had AGE-RELATED MACULAR DEGENERATION (AMD), the number one cause of blindness in Americans over age 55. Her doctor explained that there was no treatment or cure.

Although AMD can sometimes cause rapid vision loss, in Loretta’s case the disease progressed slowly over time. Today, Loretta, who is now widowed, is unable to drive, read, or clearly see the faces of friends and family. “People often think I’m ignoring them.” said Loretta, “They don’t understand that I just can’t see them. It’s very frustrating.”

For Loretta, the hardest part of living with this disease is giving up her independence. “I am completely reliant on someone else to drive me where I need to go,” said Loretta, who still goes into her Chicago office everyday. “The office is my salvation. But I do need help reading my mail and even writing checks. For someone like me who is used to being so independent, it’s hard to rely on others, but I am fortunate to have excellent support from two wonderful women working with me.”

Although AMD can often be isolating, Loretta works hard to keep up with friends and maintains a positive attitude. “My brother was a great inspiration to me, and I am proud of all of the work he did for The Foundation Fighting Blindness,” said Loretta. Bud passed away two years ago and also had vision loss from AMD, a disease which sometimes runs in families. “He never let this disease get the best of him and I try to do the same. What else can you do? You have to remain upbeat and be thankful for all the good things in your life.”

Loretta continues her brother’s tradition by supporting The Foundation Fighting Blindness and donates both her time and money to help find a cure. Now a Foundation trustee, Loretta has opened the door to families and philanthropic organizations that are in a position to further the mission of FFB.

Thanks to years of research, treatments are emerging for wet AMD, a less common form of the disease, and scientists are working on potential treatments for dry AMD, Loretta’s type.

“It’s important to contribute to the research. We all have to do our part to help find a cure. In the meantime, I take it day by day and I count my blessings.”





Up close, the black pupil and vivid iris look like the bloom of a sunflower. The iris regulates the amount of light entering the eye through the pupil.

## [2005 SCIENTIFIC ADVANCES]

The Foundation Fighting Blindness continued to persevere in areas of vital scientific research. During 2005 we saw many important advances including: the discovery of an AMD-related gene called complement factor H, emerging therapies for people with retinitis pigmentosa, new stem cell therapies, and the advancement of the most promising therapies into human clinical trials. Indeed, we left no stone unturned in our efforts to save and restore sight in people affected by devastating retinal conditions.

### **Saving Sight by the Millions**

Age-related macular degeneration (AMD) is a devastating disease robbing millions of older Americans of their vision and independence. In fact, it's the leading cause of blindness in people 55 and older. With the aging of our Baby Boomer population, more and more people are suffering from AMD everyday.

What's particularly tragic about AMD is that affected people lose their central vision, leaving them unable to drive, read, and recognize the faces of loved ones. Their loss of independence leads to a dramatic decline in their quality of life. People affected by AMD are often confined to their homes. Many develop clinical depression.

Thanks to investigators funded by The Foundation Fighting Blindness, 2005 has been a breakthrough year in AMD research. Their discovery of an AMD-related gene called complement factor H (CFH) — linked to as many as 50 percent of all cases of AMD — is perhaps the most important advancement in AMD research ever made. CFH is a gene that regulates

inflammation and immune responses. Not only is it broadly implicated in AMD, it's a clear target for identifying people at risk of the blinding disease, and developing future therapies and preventions that can minimize its impact or eradicate it entirely.



In this tissue section of the human retina, bright green demonstrates the presence of the protein product of CFH gene.

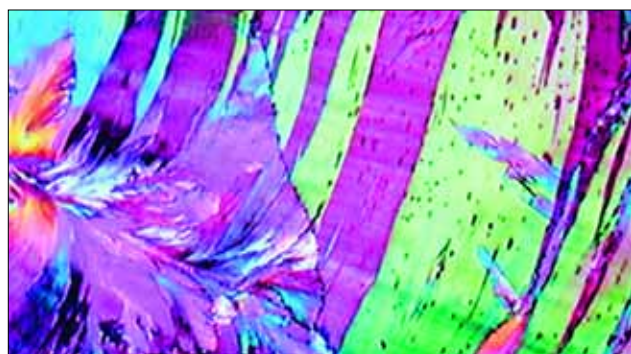
IMAGE: NEI/NIH

In addition to this giant genetic leap forward, new pharmacologic treatments for AMD are moving successfully through clinical trials — some are making it to the marketplace. These therapies were developed to halt or prevent vision loss from the more severe, later-stage form of the disease known as wet AMD.

Though much work remains to overcome AMD entirely, researchers now have a clear direction for forthcoming AMD research and treatment development efforts.

## Formidable Responses to Formidable Diseases

“Sorry, there’s nothing we can do.” For people losing their vision to retinitis pigmentosa (RP), it’s a phrase they’ve undoubtedly heard from an eye care professional in the past.



Patients exhibiting retinitis pigmentosa have DHA levels in their red blood cells that are significantly reduced (40 percent less) from that of normally sighted people. Statistical analyses show a significant correlation between cone photoreceptor function and red blood cell docosahexaenoic levels.

Because RP and related diseases are rare, there’s been little financial incentive for most commercial companies to develop preventions, treatments, and cures for them.

Thanks to funding from The Foundation, the best retinal investigators in the world are providing promise for saving and restoring the sight of people affected by RP. “Gene therapy, vision-preserving proteins, retinal transplants.” These are emerging therapies that people with RP would hear about if they talked with an investigator supported by The Foundation. Over the past 34 years, these

researchers have been relentless in their pursuit of RP preventions, treatments, and cures.

To date, investigators have identified more than 114 disease-causing genes— a process which provides experts with critical paths to therapies. As a result of these discoveries and subsequent studies, a Phase I human clinical trial will soon be underway for gene therapy to treat a severe form of RP known as Leber congenital amaurosis. Other gene therapy studies could soon be launched for choroideremia, retinoschisis, Stargardt disease, Usher syndrome and other retinal degenerative diseases.

During 2005, researchers continued to uncover other potential vision-saving therapies for retinal degenerative diseases. Treatments are showing promise for slowing the progression of Stargardt disease, dry AMD, and other conditions. A newly discovered cone-preserving protein in rods appears to slow vision loss in people with RP. A nutritional supplement called docosahexaenoic (DHA), a healthful fatty acid found in fish, can boost the vision-preserving effect of vitamin A in people with RP.

Foundation-funded researchers are leaving no stone unturned in their determination to save and restore sight in people affected by these devastating retinal conditions.

# [RETINAL DEGENERATIVE DISEASES: A PRIMER]

**Macular degeneration** is a retinal degenerative disease that causes progressive loss of central vision. Individuals with macular degeneration may first notice a blurring of central vision that is most apparent when performing visually detailed tasks such as reading and sewing. Blurred

IMAGE: NEI/NIH



central vision may also make straight lines appear slightly distorted or warped. As the disease progresses, blind spots form within central vision. In most cases, if one eye has macular degeneration, the other eye will also develop the disease. The extent of central vision loss varies according to the type of macular degeneration. The risk of developing macular degeneration increases with age.

The disease most often affects people in their sixties and seventies. Macular degeneration is the most common cause of vision loss in individuals over the age of 55. Most cases of macular degeneration occur in older people although inherited juvenile forms exist, including **Stargardt disease**, **Best’s vitelliform macular dystrophy**, **Doyme’s honeycomb retinal dystrophy**, and **Sorsby’s fundus dystrophy**.

**Retinitis pigmentosa (RP)** is the name given to a group of inherited eye diseases that affect the retina. Retinitis pigmentosa causes the degeneration of photoreceptor cells in the retina and can often lead to complete blindness. Photoreceptor cells capture and process light helping us to see. As these cells degenerate and die, patients experience progressive vision loss.

The most common feature of all forms of retinitis pigmentosa is a gradual degeneration of the rods and cones. Most forms of RP first cause the degeneration of rod cells. These forms of retinitis pigmentosa, sometimes called rod-cone dystrophy, usually begin with night blindness. Forms of RP include **Usher syndrome** (combines hearing loss with RP), **Leber congenital amaurosis**, **rod-cone disease**, **Bardet-Biedl syndrome**, and **Refsum disease**, among others.



IMAGE: NEI/NIH



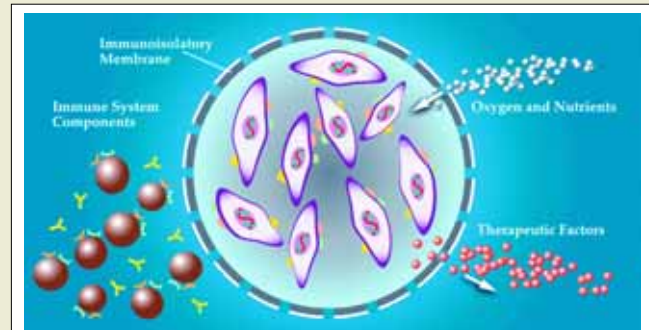


## Answers for the Most Advanced Disease

In 2005, The Foundation’s Stem Cell Research Consortium was established to aggressively advance stem cell therapies for the treatment of a variety of retinal degenerative diseases. Whether a person has RP, AMD, Usher syndrome or Stargardt disease, stem cells provide hope for the repair and regeneration of severely diseased retinal tissue. Stem cells are potentially the answer for people with the most advanced disease—people who have lost most or all of their vision. The Consortium has committed more than \$3 million through 2009 for stem cell research at the University of Wisconsin, the University of Southern California, the University of Utah, and Harvard.

Additionally, thanks to a key pre-clinical cell-based study funded by The Foundation—a study that would have otherwise not occurred—a company called Neurotech is now moving a vision-preserving therapy into a Phase II clinical trial. The therapy uses a capsule with retinal cells to deliver a protein, which can preserve vision for many people with retinal degenerative diseases, regardless of what type of condition they have.

The forthcoming Neurotech treatment is a great example of The Foundation’s commitment to filling therapy gaps; we played an essential, indispensable role in moving this promising treatment forward. Whether the need is financial, logistical, or regulatory, The Foundation does whatever it takes to bring effective treatments to the people who need them most. Our vision is their vision.



Encapsulated cell implants consisting of living cells are genetically engineered to produce desired therapeutic substances that target specific diseases or conditions.

IMAGE: NEUROTECH

## NNRI: A Strong Commitment to Clinical Trials

The past year has been pivotal at The Foundation Fighting Blindness as we move treatments from the lab into the clinic. We established the National Neurovision Research Institute (NNRI) for that very purpose — to move promising therapies into human clinical trials. Though testing potential treatments in humans involves new technical and logistical challenges, financial requirements are often the biggest hurdle. Where pre-clinical studies cost hundreds of thousands of dollars, human trials cost many millions.

A goal of NNRI is to work with individual donors, venture capitalists, academia, pharmaceutical and biotechnology companies, and government organizations to collaborate and raise money for resource-intensive human clinical trials.

Last year’s first NNRI Symposium in Washington, D.C., brought together hundreds of scientists, government representatives, corporate leaders, and venture capitalists to discuss critical financial needs, as well as numerous logistical and regulatory issues. Proceedings from the Symposium were published as a special 120-page supplement for the professional journal *Retina* to further educate the research community about our clinical efforts and goals.

Human clinical trials are the most crucial step in moving preventions, treatments, and cures forward. These studies require huge resource commitments and financial investments. But through NNRI, and continued revenue development efforts, FFB will continue to make them happen.

CORBIS

# [2005 RESEARCH GRANTS]

## FFB Research Centers

FFB has 16 “Centers” defined as a group of investigators that closely collaborate, share resources and knowledge to further their research into retinal degenerative diseases. Basic scientists are paired with clinical investigators to more quickly and innovatively approach the ultimate goal of treatments and cures. In addition to advancing research, FFB Centers provide a strong environment for the training of both young clinicians and basic scientists in the field of retinal degenerative disease.

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

\$322,773

Massachusetts Eye and Ear Infirmary

Harvard Medical School

*Eliot L. Berson, M.D.*

Center Coordinator

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

\$265,075

Cole Eye Institute

*Joe G. Hollyfield, Ph.D.*

Center Coordinator

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

\$487,329

New York University School of Medicine

Edward S. Harkness Eye Institute,

Columbia University,

University of Medicine and Dentistry,

New Jersey Medical School

*Ronald E. Carr, M.D.*

*Lucian del Priore, M.D., Ph.D.*

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

Center Co-Coordinators

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

\$334,574

University of California at San Francisco

University of California at Berkeley

Stanford University School of Medicine

*Matthew M. LaVail, Ph.D.*

Center Coordinator

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

\$328,370

University of California at Los Angeles

*Dean Bok, Ph.D.*

Center Coordinator

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

\$442,472

Moran Eye Center

University of Utah

*Wolfgang Baehr, Ph.D.*

Center Coordinator

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

\$302,913

Casey Eye Institute

*Richard G. Weleber, M.D.*

Center Coordinator

**Pre-Clinical Medical Therapy  
Evaluation Center**

\$575,351

Cornell University  
University of Pennsylvania  
*Gustavo Aguirre, V.M.D., Ph.D.*  
Center Coordinator

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

\$319,824

University College London,  
United Kingdom  
*Frederick W. Fitzke, Ph.D.*  
Center Coordinator

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

\$408,054

University of Iowa Carver  
College of Medicine  
*Edwin M. Stone, M.D., Ph.D.*  
Center Coordinator

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

\$219,000

Wallenberg Retina Center  
University Hospital of Lund, Sweden  
*Theo van Veen, Ph.D.*  
Center Coordinator

**Scheie Eye Institute Retinal  
Degeneration Research Center**

\$339,972

University of Pennsylvania  
*Samuel G. Jacobson, M.D., Ph.D.*  
Center Coordinator

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

\$344,611

Retina Foundation of the  
Southwest (Dallas)  
The University of Oklahoma Health  
Sciences Center  
The University of Texas Health  
Science Center at Houston  
*Robert E. Anderson, M.D.*  
*David Birch, Ph.D.*  
Center Co-Coordiators

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

\$157,203

University of Illinois at  
Chicago Eye Center  
*Gerald A. Fishman, M.D.*  
Center Coordinator

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

\$404,072

Johns Hopkins University  
School of Medicine  
*Peter A. Campochiaro, M.D.*  
Center Coordinator

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

\$538,303

University of Michigan  
*Anand Swaroop, Ph.D.*  
Center Coordinator

**Research Facilities**

**Retinal Degeneration Pathophysiology Facility**

\$68,802

Cole Eye Institute  
The Cleveland Clinic Foundation  
Cleveland, Ohio  
*Joe G. Hollyfield, Ph.D.*  
Facility Coordinator

**Molecular and Genetic Analysis of Patients with Choroideremia**

\$22,000

Ocular Genetics Laboratory  
University of Alberta  
Edmonton, Alberta, Canada  
*Ian MacDonald, M.D.*  
Facility Coordinator

**Resource Facility for X-linked Retinitis Pigmentosa and Age-related Macular Degeneration**

\$70,899

W.K. Kellogg Eye Center  
University of Michigan  
Ann Arbor, Michigan  
*Anand Swaroop, Ph.D.*  
Facility Coordinator

**Individual Investigator Grants**

**CELL BIOLOGY**

**Paul Sternberg, M.D.**

\$28,964

Vanderbilt University Medical Center  
Nashville, Tennessee

**David S. Williams, Ph.D.**

\$79,962

University of California at  
San Diego School of Medicine  
La Jolla, California

**CLINICAL STUDIES**

**Johanna Seddon, M.D.**

\$42,362

Massachusetts Eye and Ear Infirmary  
Harvard Medical School  
Boston, Massachusetts

**Johanna Seddon, M.D.**

\$60,000

Massachusetts Eye and Ear Infirmary  
Harvard Medical School  
Boston, Massachusetts

**GENE THERAPY**

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

\$70,000

Scheie Eye Institute  
University of Pennsylvania  
Philadelphia, Pennsylvania

**John Flannery, Ph.D.**

\$594,023

The Kern Family Center for  
the Study of Retinal Degeneration  
University of California at Berkeley  
Berkeley, California

**William Hauswirth, Ph.D. and Alfred Lewin, Ph.D.**

\$75,084

Department of Ophthalmology  
University of Florida College of Medicine  
Gainesville, Florida

**Robert S. Molday, Ph.D.**

\$80,000

The Centre For Macular Research  
University of British Columbia  
Vancouver, Canada

**David S. Williams, Ph.D.**

\$95,000

University of California at  
San Diego School of Medicine  
La Jolla, California

**GENETIC STUDIES**

**Shomi S. Bhattacharya, Ph.D.**

\$73,988

Research Center at the Institute  
of Ophthalmology  
Moorfields Eye Hospital  
London, England

**F.P.M. Cremers, Ph.D.**

\$58,310

Department of Human Genetics  
University Medical Center Nijmegen  
Nijmegen, The Netherlands

**George Inana, M.D., Ph.D.**

\$63,654

Bascom Palmer Eye Institute  
University of Miami  
Miami, Florida

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

\$79,567

Hospital Necker-Enfants Malades  
Paris, France

**Bronya Keats, Ph.D.**

\$63,654

Louisiana State University Medical Center  
New Orleans, Louisiana

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

\$63,653

Boys Town National Research Hospital  
Omaha, Nebraska

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

\$66,930

Scheie Eye Institute  
University of Pennsylvania  
Philadelphia, Pennsylvania

**Dennis W. Schultz, Ph.D.**

\$56,650

Oregon Health Sciences University  
Portland, Oregon

**Kent W. Small, M.D.**

\$62,355

Cedars-Sinai Medical Center  
Los Angeles, California

**Edwin M. Stone, M.D., Ph.D.**

\$79,567

University of Iowa Carver  
College of Medicine  
Iowa City, Iowa

**PHARMACEUTICAL THERAPY****Jeffrey H. Boatright, Ph.D.**

\$43,126

Emory University  
Atlanta, Georgia

**Ken Widder, M.D.**

\$30,000

Sytera, Inc.  
La Jolla, California

**PRE-CLINICAL STUDIES****Gregory M. Acland, B.V.Sc.**

\$104,491

University of Pennsylvania  
Kennett Square, Pennsylvania

**Alfredo Garcia-Layana, M.D., Ph.D.**

\$23,610

University of Navarra  
Navarra, Spain

**Ivan Y. Leung, Ph.D.**

\$9,000

Wilmer Eye Institute  
Johns Hopkins University  
School of Medicine  
Baltimore, Maryland

**Tiansen Li, Ph.D.**

\$66,595

Berman-Gund Laboratory for the  
Study of Retinal Degenerations  
Massachusetts Eye and Ear Infirmary  
Harvard Medical School  
Boston, Massachusetts

**Muna I. Naash, Ph.D.**

\$80,236

University of Oklahoma Health  
Sciences Center  
Norman, Oklahoma

**Miguel Seabra, M.D., Ph.D.**

\$65,776

Imperial College of Science  
London, England

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

\$25,462

Columbia University Medical Center  
New York, New York

## TRANSPLANTATION STUDIES

**Judith A. Kapp, Ph.D.**

\$120,685

University of Alabama at Birmingham  
Birmingham, Alabama

**Srinivas R. Sadda, M.D.**

\$60,000

Doheny Eye Institute  
University of Southern California  
Los Angeles, California

## Career Development Awards

**Tomas Aleman, M.D.**

\$50,000

Scheie Eye Institute  
University of Pennsylvania  
Philadelphia, Pennsylvania

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

\$25,000

Doheny Eye Institute  
University of Southern California  
Los Angeles, California

**Melanie Sohocki, Ph.D.**

\$50,000

Columbia University Medical Center  
New York, New York

**Debora B. Farber, Ph.D.**

\$38,192

Jules Stein Eye Institute  
University of California at Los Angeles  
Los Angeles, California

## Meetings/Workshops

**2005 FASEB Meeting**

“The Biology and Chemistry of Vision”

June 18 - 23

Tucson, Arizona

\$5,000

**American Association of Immunologists Meeting**

“Biologic Relevance and Therapeutic  
Implications of Immune Privilege”

April 2 - 6

San Diego, California

\$1,000

**Patsy M. Nishina, Ph.D.**

“The Laboratory Mouse in Vision Research”

Jackson Laboratory

Bar Harbor, Maine

\$2,500

## Board of Trustee Award

**Jose´ A. Sahel, M.D. and**

**Thierry Leveillard, Ph.D.**

\$25,000

Centre Hospitalier National  
d’Ophtalmologie des Quinze-Vingts  
Paris, France

# [NATIONAL NEUROVISION RESEARCH INSTITUTE]

The mission of the National Neurovision Research Institute is to accelerate the translation of laboratory based research into clinical trials for treatments and cures of retinal degenerative diseases.

The Foundation Fighting Blindness was founded in 1971 to provide seed money for investigators to initiate innovative research in inherited retinal diseases. FFB has supported many pilot projects, which have then advanced to meet the stringent funding requirements of the National Eye Institute (NEI). FFB and NEI are informal collaborators and, together, are major forces in developing therapies for inherited retinal diseases.

Over the years, research initiatives by FFB, NEI, and others have led to many major developments in the field, mostly at the fundamental and laboratory level. However, human therapies are emerging from the laboratory now, following proof of principle from in vitro studies and animal models. The opportunity for clinically relevant work is now rapidly evolving. A large gap still exists, however, between potential therapies coming out of the laboratory and therapies proven to be both safe and effective in humans—and, therefore, routinely available to patients in the marketplace. The National Neurovision Research Institute was founded in 2003 to facilitate cooperation among the Government, academic, pharmaceutical, biotech and financial communities to expedite the translation of these therapies from the laboratory to the clinic. NNRI is a non-profit wholly-owned subsidiary of The Foundation Fighting Blindness.

## Pre-clinical Assessment Centers\*

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

\$60,000

Wilmer Eye Institute  
Johns Hopkins Hospital  
Baltimore, Maryland

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

\$60,000

Wallenberg Retina Center  
University Hospital of Lund  
Lund, Sweden

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

\$60,000

Scheie Eye Institute  
University of Pennsylvania  
Philadelphia, Pennsylvania

## Individual Investigator Grants

### TRANSPLANTATION STUDIES

**Norman Radtke, M.D.**

\$225,000

University of Louisville  
School of Medicine  
Louisville, Kentucky

**Kang Zhang, M.D., Ph.D.**

\$119,000

University of Utah  
Salt Lake City, Utah



\*Funded by FFB in FY 2005

# [2005 FINANCIAL REPORT]

## A Message from Our Treasurer

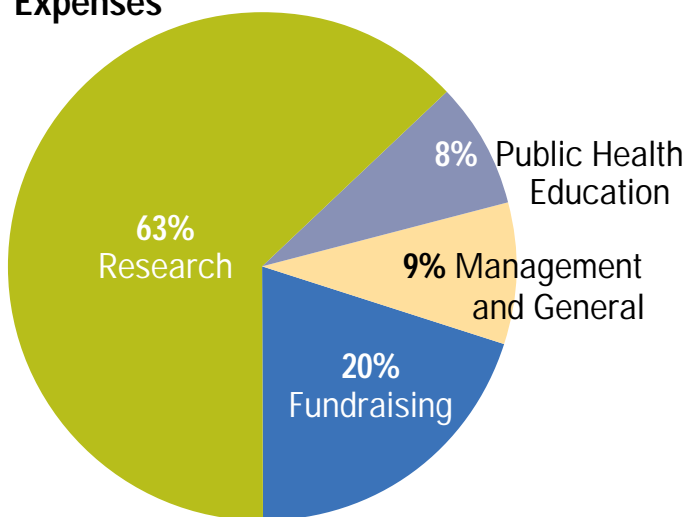
I am pleased to present The Foundation Fighting Blindness' Statements of Financial Position and Activities. In fiscal year 2005, \$10.9 million dollars was spent on research. This represents a \$600,000 increase over last fiscal year allowing even more money to go to promising research projects at prominent institutions around the country and around the world. In addition, more than \$1.4 million was spent on public health education programs which help to inform and support those affected by retinal degenerative diseases.

Our financial statements were audited by Raffa, P.C. independent certified public accountants. 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).

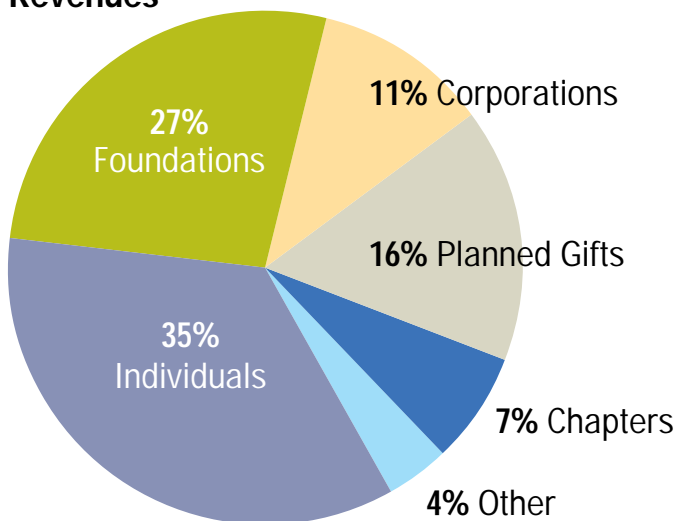


William J. Chatlos  
Treasurer

### Expenses



### Revenues





**Statement of Financial Position**

**Assets**

Cash and Investments	\$ 7,397,035
Pledges Receivable, Net	441,182
Other Assets	693,003
Trusts and Other Funds	4,174,025
Fixed Assets, Net	<u>1,652,290</u>
<b>Total Assets</b>	<b><u>\$ 14,357,535</u></b>

**Liabilities**

Accounts Payable and Accrued Liabilities	\$ 1,287,778
Research Grants Payable	1,768,749
Deferred Revenues	354,529
Liabilities under Trusts and Other Funds	<u>1,215,431</u>
<b>Total Liabilities</b>	<b><u>\$ 4,626,487</u></b>

**Net Assets**

Unrestricted	\$ 1,286,523
Board Designated for Future Opportunities	3,000,000
Board Designated for Expansion of Research Facility Represented by Fixed Assets	172,000
Temporarily Restricted Net Assets	1,652,290
Permanently Restricted Net Assets	<u>3,120,235</u>
<b>Total Net Assets</b>	<b><u>\$ 9,731,048</u></b>
<b>Total Liabilities and Net Assets</b>	<b><u>\$ 14,357,535</u></b>

**Statement of Activities**

**Public Support and Other Revenue**

Contributions	\$ 12,584,661
Special Events, Net of Direct	4,046,048
Bequests	764,361
Other Revenue	<u>784,025</u>
<b>Total Revenue</b>	<b><u>\$ 18,179,095</u></b>

**Expenses**

Research	\$ 10,851,053
Public Health Education	1,429,706
Management	1,510,398
Fundraising	<u>3,367,405</u>
<b>Total Expenses</b>	<b><u>\$ 17,158,562</u></b>

<b>Net Revenue Unrestricted</b>	<b>\$ (219,788)</b>
<b>Net Revenue Restricted</b>	<b><u>1,240,321</u></b>
<b>Total Net Revenue</b>	<b><u>\$ 1,020,533</u></b>

## [HOW YOU CAN HELP]



CORBIS

There are many ways that you can help The Foundation Fighting Blindness speed the pace of research. Your support will make a difference.

### **Outright Gifts**

Outright gifts in the form of cash, securities, real estate and personal property provide much-needed financial support and have an immediate impact.

### **Cash**

Checks made out to The Foundation Fighting Blindness can be sent to P.O. Box 17279, Baltimore, MD 21203-7279. Or visit our website, [www.FightBlindness.org](http://www.FightBlindness.org) to make an immediate and secure online donation.

### **Gifts of Real Estate and Financial Securities**

When you give a gift of real property, stocks or bonds, you may claim an income tax charitable deduction based on the full market value of the gift, avoid capital gains taxes on appreciated value, and eliminate certain costs associated with the transfer of real property.

### **Personal Property**

The Foundation accepts a wide variety of personal possessions, such as works of art, valuable collectibles, or antiques.

**Planned Giving**

Planned Giving is an important way for you to financially plan today to make a substantial gift to FFB, either now or in the future. Typical planned gifts include bequests, trusts, and gift annuities. To receive information about any of our planned giving programs, call 800-683-5555 ext. 1170.

**Charitable Gift Annuity**

The charitable gift annuity is one of the most secure forms of generating income for you, while making a gift to FFB. A charitable gift annuity is an agreement by an individual 60 and over to give a sum of money or property to a charitable organization, and in return, receive a guaranteed fixed income for life. Unlike bequests, the gift annuity produces income to the donor throughout his or her lifetime.

**Wills, Bequests and Trusts**

You may also help FFB through a bequest in your will or living trust. You may designate FFB as a beneficiary of all or a portion of your estate. Also you may donate a remainder of your estate after expenses and gifts to your family and friends, or designate a trust for use by a family member during his or her lifetime. You can include estate assets such as real estate, jewelry, valuable collectibles, art and antiques.

**Unrestricted Gifts**

When you do not restrict the use of your gift, you give the Foundation flexibility to meet changing or urgent needs such as funding promising new research initiatives.

**Volunteering**

Besides your financial support, your individual talents and professional associations can be enormously useful to The Foundation. Whether you are interested in assuming a leadership role in your community or helping out at one of our many fundraising events around the country, your support is needed! Please call 800-683-5555 for more information.

**Tribute Gifts**

Many FFB supporters use Tribute Gifts as a way of honoring an individual, commemorating a special occasion, or memorializing a friend or family member. FFB will notify the person or family being acknowledged without mention of the gift amount. Tribute gifts may be sent to **The Foundation Fighting Blindness, P.O. Box 17279, Baltimore, MD 21203-7279** or made through our website [www.FightBlindness.org](http://www.FightBlindness.org). Please include the name and address of those to be notified and the occasion or reason for the tribute.

**Because The Foundation Fighting Blindness is a non-profit 501(c)3 organization, contributions are tax deductible to the full extent allowed by law.**

# [ LEADERSHIP ]



Gordon Gund



Jeremiah H. Shaw, Sr.



Edward H. Gollob



Joel P. Davis



David B. Brint



Yvonne E. Chester



William J. Chatlos



Bruce P. Sawyer

## Board of Directors

Gordon Gund  
*Chairman*

Jeremiah H. Shaw, Sr.  
*Vice Chairman*

Edward H. Gollob  
*President*

Joel P. Davis  
*Senior Vice President*

David B. Brint  
*Vice President*

Yvonne E. Chester  
*Secretary*

William J. Chatlos  
*Treasurer*

Bruce P. Sawyer  
*Assistant Treasurer*

Gregory A. Austin  
Daniel G. Bergstein

Marilyn Green

Howard Hirsch

Alan R. Kahn

Haynes P. Lea

Betti Lidsky

Edward C. McNally

Igor Olenicoff

Edward Russnow

Deborah Shaw

George G. Villere

David G. Walsh

Theodore M. Welp

**National Trustees**

Clifford B. Aaron  
 David T. Alexander  
 Terry Pink Alexander  
 Pamela J. Allen  
 Steven D. Alper  
 Norman Barkeley  
 Michele A. Molloy Barnett  
 Stephen C. Barnett  
 Jordan S. Bergstein  
 Beverly Berman  
 Thomas L. Bernardin  
 Joseph Bier  
 Denice F. Brown  
 Scott W. Burt  
 William E. Carty  
 Robert D. Cleveland  
 Peter Coster  
 Joan E. Crowley  
 Peter J. Crowley  
 Thomas W. Curley  
 Sallie W. Cushner  
 Glen Davidson  
 Daniel P. Day  
 Steven Dezii  
 Ralph L. Donnelly  
 Cynthia Elden  
 Richard Elden  
 David Finkelstein  
 Harriet L. Finkelstein  
 Bill Fischer  
 Daniel Freedman  
 Edward L. Goldberg  
 Ramon Gomez  
 Dean Green  
 Bruce Grieve  
 Llura Gund  
 Lawrence S. Halperin, M.D.  
 Melissa Campbell Harris, M.D.  
 Loretta Hoffelder  
 Charlotte Isen  
 Leslie James  
 William F. James, Jr.  
 Tracy E. Johns  
 Thomas A. Jones

Alan B. Landis  
 Linda Lechner  
 Carlos Lidsky  
 Nathan Light  
 Patricia A. Light  
 Richard Lynch  
 Stephen A. Mack  
 Ronald E. Massman  
 Beatrice C. Mayer  
 M. Rose McCain  
 Patrick J. McGuinn  
 James P. McNiel  
 Nancy Mendelow  
 Sean Moynihan  
 Jacob A. Myers  
 Harry P. Oakes  
 Karen Petrou  
 Louis D. Posen  
 Ann Rasch  
 Ken Rietz  
 John Saclarides  
 Melville R. V. Sahyun Ph.D.  
 Ira Schulman  
 Stanley Shapiro  
 Moira Shea  
 Stephen B. Siegel  
 Mary Silverthorne  
 Jonathan S. Steinberg, M.D.  
 Evan Stone  
 Steffen Suchert  
 Frank Trainor  
 Meredith Tyree  
 Elaine Welp  
 Peter Whinfrey  
 John M. Wilson, Jr.  
 Stephen A. Wynn  
 Roy Timothy Young

**Trustees Emeritus:**

Bernard Berman (1924–1996)  
*President*  
 Daniel Freedman  
*Vice President*  
 Stanley Rosenberg  
 Alexander Yankelove

**Scientific Advisory Board**

**Chairman**

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

**Vice Chairs**

*Alan M. Laties, M.D.*  
*Raymond D. Lund, Ph.D., FRS*  
*Richard G. Weleber, M.D.*  
*Marco Zarbin, M.D., Ph.D.*

Gustavo Aguirre, V.M.D., Ph.D.  
 Robert E. Anderson, M.D., Ph.D.  
 Radha Ayyagari, Ph.D.  
 Jean Bennett, M.D., Ph.D.  
 Paul S. Bernstein, M.D., Ph.D.  
 Eliot L. Berson, M.D.  
 David G. Birch, Ph.D.  
 Mark S. Blumenkranz, M.D.  
 Dean Bok, Ph.D.  
 Stephen P. Daiger, Ph.D.  
 Eugene de Juan, Jr., M.D.  
 Lucian V. Del Priore, M.D., Ph.D.  
 John E. Dowling, Ph.D.  
 Thaddeus P. Dryja, M.D.  
 Debora Farber, Ph.D.  
 Gerald A. Fishman, M.D.  
 John Flannery, Ph.D.  
 Morton F. Goldberg, M.D.  
 Gregory S. Hageman, Ph.D.  
 William W. Hauswirth, Ph.D.  
 Joe G. Hollyfield, Ph.D.  
 Leslie G. Hyman, Ph.D.  
 Samuel G. Jacobson, M.D., Ph.D.  
 William J. Kimberling, Ph.D.  
 Matthew M. LaVail, Ph.D.  
 Vincent H. L. Lee, Ph.D.  
 Tiansen Li, Ph.D.  
 Roderick R. McInnes, M.D., Ph.D.  
 Jeremy Nathans, M.D., Ph.D.  
 Gary D. Novack, Ph.D.  
 Robert R. Rando, Ph.D.  
 Thomas Reh, Ph.D.  
 José A. Sahel, M.D.  
 Johanna M. Seddon, M.D.  
 Edwin Stone, M.D., Ph.D.  
 Andreas Wenzel, Ph.D.  
 Michael J. Young, Ph.D.  
 Donald J. Zack, M.D., Ph.D.

## Management Staff

William T. Schmidt  
*Chief Executive Officer*

Randall A. Hove  
*Chief Operating Officer*

James W. Minow  
*Chief Development Officer*

Stephen M. Rose, Ph.D.  
*Chief Research Officer*

Ruth E. Shields, CPA  
*Chief Financial Officer*

Diane Bovenkamp, Ph.D.  
*Director of Science  
Information and Programs*

Susan Brumley  
*Senior Director,  
Southern Region*

Judy Gildee  
*Director of Information  
& Technology*

John Hurst, Ph.D.  
*Grants and Awards  
Program Director*

Allie Laban-Baker  
*Director of Public Awareness  
and Communications*

Michele Mercer  
*Director of Database Operations*

Diane Redd  
*National Director, Corporate  
and Foundation Relations*

Wendy Sutherland  
*Senior Director,  
Western Region*

Pamela Weissman  
*Director of Human Resources*

Kristin White  
*National Director of Events*



William T. Schmidt



Randall A. Hove



James W. Minow



Stephen M. Rose



Ruth E. Shields

## Regional Development Offices

Susan Abderholden  
Midwest Development Office  
(847) 680-0100

Mari Bacon  
Florida Office  
(954) 753-4847

Susan DeRemer  
Southern California Office  
(310) 207-2089

Lauren Winarsky  
New York Metro Office  
(212) 551-7807

## National Neurovision Research Institute

### Directors and Officers

Morton F. Goldberg, M.D.  
*Chairman*

William T. Schmidt  
*President*

Randall A. Hove  
*Secretary*

Ruth E. Shields, CPA  
*Treasurer*

David Brint  
Gerald Cagle, Ph.D.  
Edward Gollob  
Gordon Gund  
Lester Kaplan, Ph.D.  
Paul Manning

Tim Schoen, Ph.D.  
*Director, Pre-clinical  
Assessment Program*

The Foundation Fighting Blindness has chapters in the following states: Alaska, Arizona, California, Colorado, Florida, Georgia, Illinois, Indiana, Kentucky, Maryland, Massachusetts, Michigan, Minnesota, Missouri, Nebraska, New Jersey, New York, North Carolina, Pennsylvania, Tennessee, Texas, Utah, Virginia and Wisconsin.

The Foundation Fighting Blindness, Inc. is a 501(c)(3) organization as determined by the Internal Revenue Service and is approved by the Office of Personnel Management for participation in the Combined Federal Campaign (#1714).



**Foundation** □  
**Fighting Blindness**

Driving research to save & restore sight □

THE FOUNDATION FIGHTING BLINDNESS, INC.

11435 Cronhill Drive

Owings Mills, Maryland 21117-2220

410-568-0150

800-683-5555

410-363-2393 fax

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