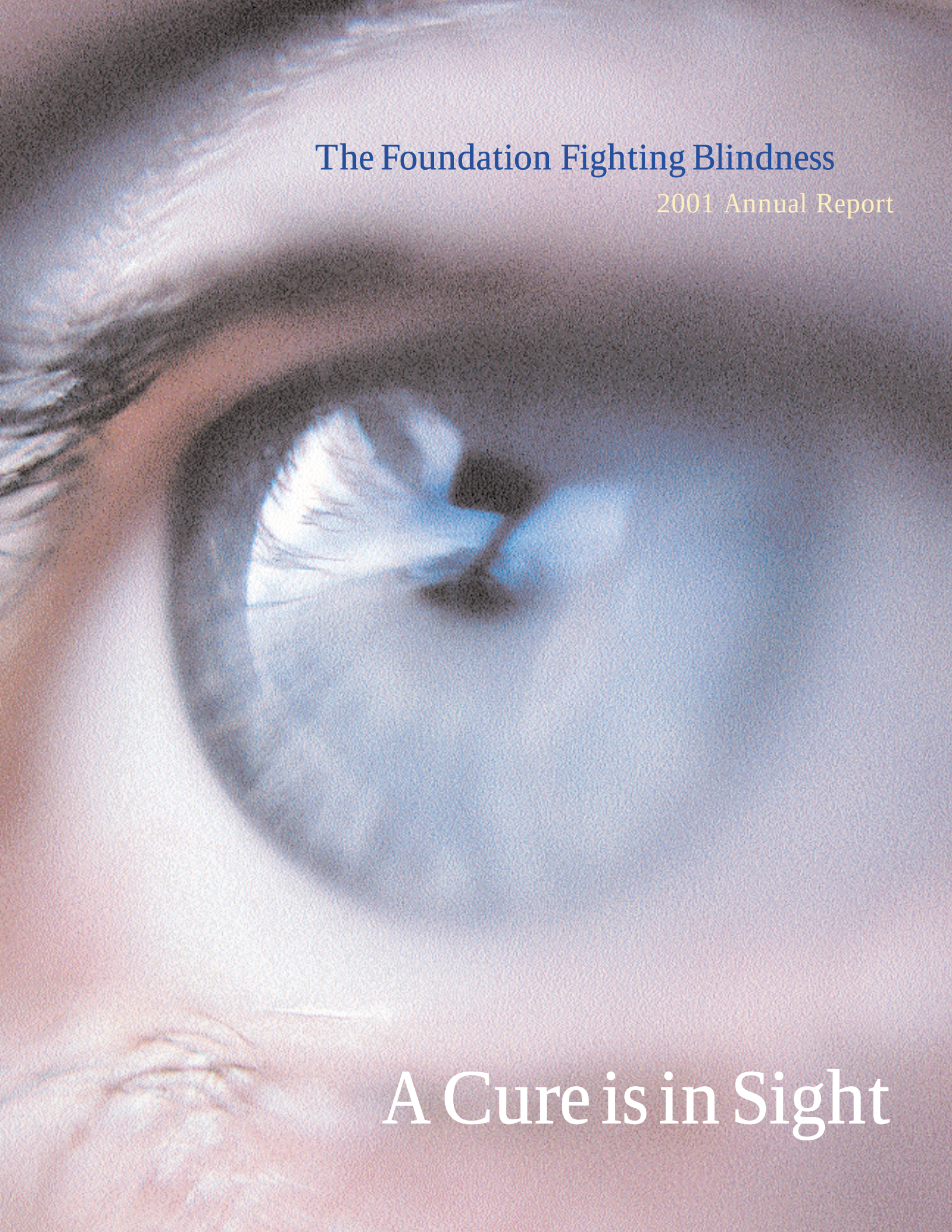


# The Foundation Fighting Blindness

2001 Annual Report

# A Cure is in Sight

Table of Contents


2 Trustees' Message

4 Chief Executive Officer's Message

16 Chief Scientific Officer's Message

20 Research Program

26 Audited Financial Statements

40 Scientific Advisory Board/Trustees

The urgent mission of The Foundation Fighting Blindness is to discover the causes, treatments, preventions and cures for retinitis pigmentosa, macular degeneration, Usher syndrome and the entire spectrum of retinal degenerative diseases.

# A Message from Our Trustees

In 1971 The Foundation Fighting Blindness began its mission to find treatments and cures for retinal degenerative diseases. We mark our 30th year with news that is truly worthy of celebration! This year, Foundation researchers used gene therapy to restore vision in dogs (see page 9). Although there is still work to be done, the opportunity to advance promising treatments to human clinical trials is now firmly within our reach.

The Foundation's trustees, research advisors, staff and volunteers are working hard to insure that progress continues and accelerates. Fiscal year 2001 is the fourth year of a five-year plan developed by our Fundraising and Operations Strategy Team in the fall of 1997 in conjunction with the development at the same time of a five-year research strategy plan. These teams evaluated every facet of the organization and developed a comprehensive game plan to guarantee that The Foundation maximizes its fundraising and research potential. Since then exciting progress has been made in many areas of our research program. We are pleased to report that The Foundation is ahead of the fundraising goals set forth in the plan. In fiscal year 2001, The Foundation raised $17,768,278 in unrestricted revenue, a 12% increase over last year. Despite this growth, scientific opportunity still far outpaces our ability to fund all the research grants we receive.

The Revenue Allocation Chart on the facing page confirms The Foundation's consistent and strong commitment to research. Throughout its history, The Foundation has been consistently rated #1 among large medical research charities for the percentage of funds that go to research, as ranked by the National Health Council.

As we head toward clinical trials, research needs will become even greater. For every promising experimental therapy, toxicity studies must be completed to better gauge the safety of the treatment. The long-term effectiveness of the therapy must also be evaluated. Patients will need to be genotyped for possible inclusion in a clinical trial. Ophthalmology care facilities must be enhanced. These critical research needs make it all the more important for us to remain faithful to our mission.

## TOTAL REVENUE ALLOCATION 1971 - 2001

| | |
|---|---|
| Research | $111,995,000 |
| Public Health Education | $11,531,000 |
| Human Services | $7,860,000 |
| Management and General | $10,940,000 |
| Fundraising | $18,774,000 |

The theologian, St. Augustine wrote, "Faith is believing what you do not see; the reward of faith is to see what you believe." Thirty years ago we had nothing but faith to sustain us. Since that time, Foundation scientists have isolated and cloned over 60 mutant genes that cause retinal degeneration. As each new mutant gene is found, more patients become potential candidates for gene therapy. Foundation scientists have pioneered pharmaceutical research, discovering several drugs that preserve vision in animal models. Our efforts with industry to develop safe and effective drug delivery devices (see page 16) could soon advance drug therapies to clinical trials. The first artificial retinas, made of computer chips, have been implanted in humans (see page 18). With the discovery of adult retinal stem cells, we may at last have the means to transplant diseased retinas.

The rewards of our faith are now clearly visible. On behalf of the Board of Trustees and the millions of people affected by retinal degenerative diseases, we thank all of the many people who have made these astonishing advances possible. Together, there is a cure in sight!

Gordon Gund
Chairman

Edward H. Gollob
President

Harriet L. Finkelstein
Vice Chairman

Peter K. Whinfrey
Senior Vice President

# A Message from Our Chief Executive Officer, Robert M. Gray

In the 1939 classic, "Mr. Smith Goes to Washington," Senator Jefferson Smith, a wide-eyed optimist (played by a very young Jimmy Stewart), brings his fresh-faced ideals to Washington and, in the film's dramatic conclusion, summons up the very hopes and dreams of all Americans.

For all of us at The Foundation Fighting Blindness, "Lancelot," the first dog with a severe form of RP to have his vision restored through gene therapy, represents our hopes and dreams for a future without darkness. And like Smith, we knew that Lancelot could deliver our message to Capitol Hill about the importance of research in a unique and powerful way.

Restoring Lancelot's sight was the result of research funded jointly by The Foundation Fighting Blindness and The National Eye Institute (NEI) and is a sterling example of how our private/public partnership can reap great rewards and help drive us closer towards our mutual objective.

Funding increases for NEI are key to accelerating research. To that end, on October 9, 2001, The Foundation joined with Representative Bill Young and Senator Tom Harkin to honor Secretary of Health and Human Services Tommy Thompson at a special event in Washington which brought together more than 100 key leaders from Capitol Hill, The National Institutes of Health (NIH), NEI, and The Department of Health and Human Services.

Thompson was commended for his "Outstanding Commitment to the Health and Welfare of All Americans" and in turn, Thompson commended The Foundation for thirty years of commitment to research.

L to R: Ed Gollob, Pres. FFB; Sen. Harkin; Rep. Ros-Lehtinen;
Gordon Gund, Chairman, FFB; Sec. Thompson; Rep. Young; and Lancelot

The event also gave us an opportunity to introduce Lancelot and by all accounts, he made a tremendous impression on lawmakers. But it was also Congressional visits made by many of you and the numerous letters that you sent to your Members of Congress throughout the year to encourage the doubling of the NIH budget and an increase for NEI that made the difference. We are very optimistic that both the House and the Senate will allocate increased funding to the NIH and NEI. Additional funding for NEI means new projects on retinal degenerative diseases can be reviewed and funded.

In addition to our partnership with NEI, we recognize that pharmaceutical companies and their considerable resources play a critical role in the quest to eradicate retinal degenerative diseases. We are moving ahead with our comprehensive Medical Therapy Program to reach out to those companies that have the potential to accelerate treatments and cures. Through this program, The Foundation helps companies partner with academic scientists, maximize their research and development budgets, and plan relevant pre-clinical and clinical studies to provide the groundwork for clinical trials.

All of our recent scientific discoveries are evidence that years of sound research investment and perseverance are paying off. By continuing to work with other groups, I believe we can hasten research findings and succeed in our urgent mission. Together, there is a cure in sight.

Robert M. Gray

Chief Executive Officer

# Cindy Elden

## Living with Usher syndrome

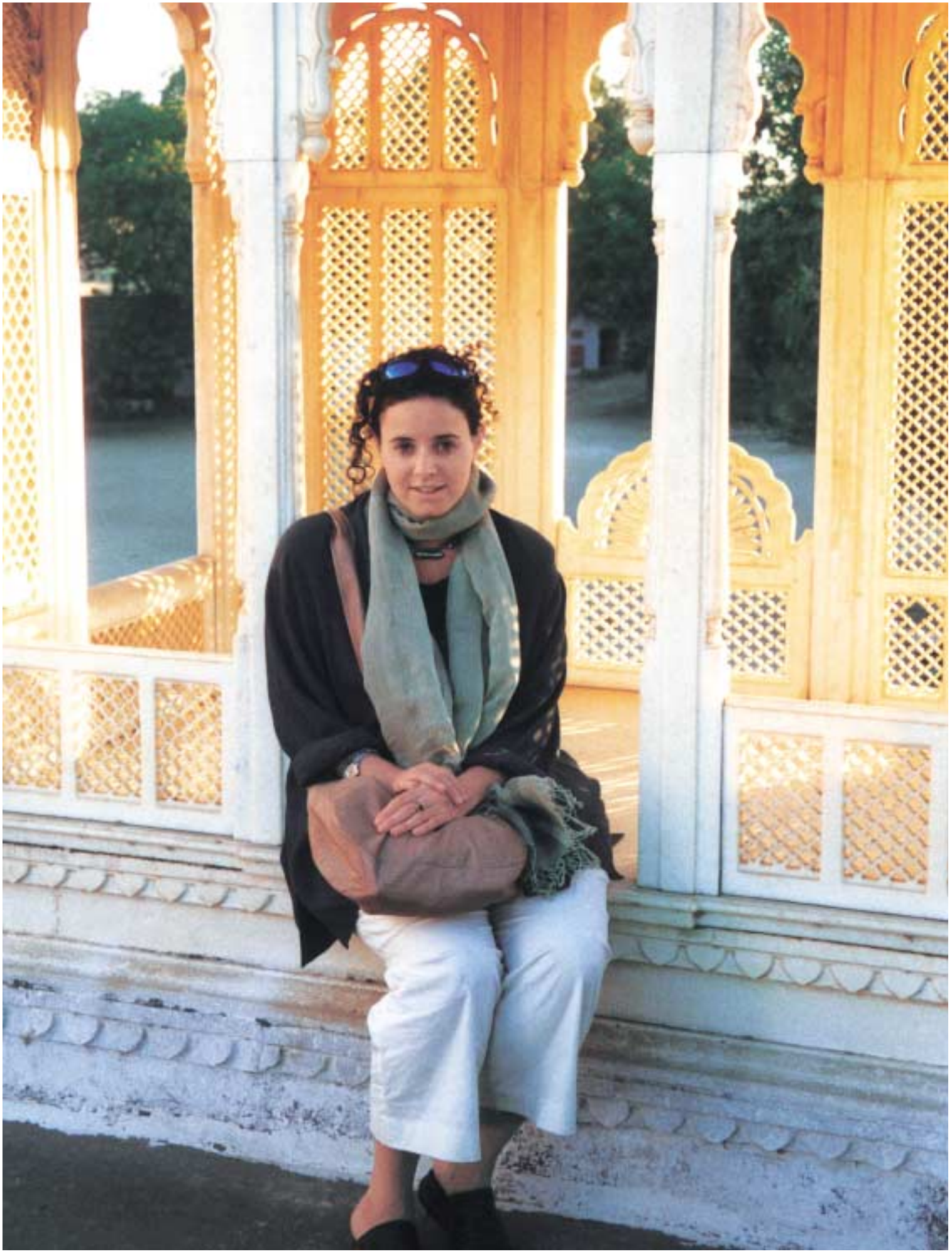
All day long, Cindy Elden is surrounded by beautiful art. Exquisite Vietnamese pottery, brightly colored Indian prints and bold Tibetan sculpture are just some of the pieces that cross Cindy's desk on a daily basis. As part of her job, Cindy, a Southeast Asian Art expert living in New York, is responsible for assessing the art that comes across her desk and determining its value for auction. "I am so lucky to be able see all of these beautiful pieces of artwork every day," says Cindy. "They are magnificent."

Cindy, 30, first fell in love with Asian art when she was studying at a prestigious art institute in London. That love led her to extensively travel throughout Asia and to eventually live in Malaysia for a short time before returning to London and then finally settling down in the Big Apple. That Cindy has accomplished so much at an early age is remarkable. What is even more remarkable is that Cindy has Usher syndrome, a disease that tragically combines hearing loss with retinitis pigmentosa, a retinal degenerative disease. Usher syndrome is the leading cause of deaf blindness in the world.

Cindy, a Chicago native, was diagnosed with hearing loss when she was a small child and has worn hearing aids for as long as she can remember. But it wasn't until Cindy was 18 that she heard the devastating news that she also had retinitis pigmentosa, a disease that is slowly stealing her vision.

Shell-shocked at first, Cindy was not about to let her diagnosis suppress her indomitable spirit. An avid skier, Cindy headed to Colorado to attend the University of Denver where she was a double major in art history and psychology. In her junior year she went to London to attend Yale University's Paul Mellon Center for studies in British Art. From there it was on to Asia. Cindy gives a great deal of credit to her parents for her accomplishments. "I know that my parents worry like mad about my hearing and vision loss and that they instinctively want to shelter me," says Cindy, "but I give them a lot of credit for being able to let go so that I could follow my dreams."

While Cindy has noticed her vision continue to deteriorate over the years, she is not a woman who spends a lot of time feeling sorry for herself. "While my vision loss is always in the back of my mind I don't spend a lot of time right now worrying about 'what ifs,'" says Cindy. "With all the research that The Foundation is funding, I am very excited and extremely hopeful about the future. Naturally, I would like things to move more quickly and get to clinical trials. We need to continue to press ahead, time is of the essence and there are so many beautiful places and great works of art yet to see."



# Lancelot: A Seeing Eye Dog

This year, a Briard dog named Lancelot gave new meaning to the term "seeing eye dog." Lancelot was born blind from a severe, early-onset form of retinitis pigmentosa called Leber congenital amaurosis. However, thanks to an amazing gene therapy breakthrough, Lancelot and three of his littermates can now see.

This finding represents the first time Foundation and National Eye Institute researchers successfully restored vision in a large animal model of retinal degeneration. That researchers can restore vision in the most severe form of retinal degeneration suggests that sight-restoring treatments are also possible for other diseases. With this study, gene therapy has overcome a major hurdle on the path to clinical trials. Genetic medicine is now making things we could only once dream of a reality.

Lancelot is a true Foundation success story. The Foundation provided funding to clone the mutant gene that causes this form of severe RP. Foundation-supported scientists also cloned the same mutant gene in the Briard dog. These discoveries provided the tools to test gene therapy in Lancelot and his littermates. After treatment, electroretinogram (ERG) tests measured a remarkable improvement in retinal function in the treated right eyes. By contrast, the untreated left eyes had almost no detectable ERG. Behavioral testing revealed that the dogs had regained ambulatory vision, seeing well enough to avoid obstacles even under dim lighting conditions. Importantly, Lancelot remains sighted many months after treatment.

Thanks goes to all of the researchers who made this breakthrough possible: Drs. Gregory Acland and Gustavo Aguirre from The Foundation's Research Center at Cornell University; Drs. Jean Bennett, Albert Maguire, and Samuel Jacobson of the Foundation's Research Center at the Scheie Eye Institute, University of Pennsylvania; and Dr. William Hauswirth at the University of Florida.

The Foundation is committed to advancing gene therapy and other treatments for all forms of retinal degeneration. This commitment will take an enormous investment on the part of all who support The Foundation in its mission to treat and ultimately cure retinal degenerative diseases. Clearly, we hold the future in our hands.

FFB Chairman and Co-Founder Gordon Gund, blind from RP for over 30 years, and Lancelot

# Mike Farina

## Living with retinitis pigmentosa

Mike Farina is a little boy who loves life. Like most nine-year-olds, he loves action-packed video games, Pokemon, his friends and ferocious dinosaurs. But unfortunately, Mike, a boy with gleaming brown eyes and a radiant smile, is not exactly like other kids his age. Mike has retinitis pigmentosa, a disease that is slowly stealing his vision.

About five years ago Mike's mom and dad, Carol and Michael, first noticed that something wasn't quite right. "We were watching a beautiful comet streak across the sky and I was surprised when little Michael couldn't see it," said Carol. "A week later, we tried to point out a rabbit perched prominently on our lawn. Again, Mike couldn't see it. We knew something was wrong." Just months later, the Farinas learned that Mike had RP. "I'll never forget the day I learned that my son was losing his vision," said Michael, his voice cracking with emotion. "I couldn't believe what was happening to my little boy. I grieved deeply over the loss of his sight and kept thinking how sad it was he might never be able to see his own children. Being able to see my beautiful son is, for me, one of life's greatest joys. Knowing Mike might never have that same experience was devastating."

For now, the Farinas are struggling with how to prepare their happy little boy for a world of potential darkness. "We are looking into special computer devices that assist the visually impaired and we sometimes try to gently prod him towards an interest in less visual things such as music," says Michael. Carol also wants to prime her son for what the future might bring. "We want to prepare him because we know that as he gets older, Mommy and Daddy won't always be there to protect him. And although we know it's not going to be easy, we want him be as independent as possible. We need to find a way for Mike to live a happy life no matter what happens."

While the Farinas are preparing for the worst, they are also very optimistic about all of the recent scientific advances. "We have been very impressed by the work of The Foundation Fighting Blindness and the scientists they fund," says Carol. "It is an exciting time. Quite frankly, without The Foundation and the work of (Foundation Chairman) Gordon Gund, we wouldn't have the hope we have today. I feel confident that the cures will come. It's a hope I hold on to."

In the meantime, Carol and Michael are working to "fill up" their son with as many wonderful images as possible while he still has some of his sight left. "We are trying to take him to see as many places as we can," says Michael. "And lots of folks are sending us beautiful photographs to share with Mike. There is so much to show him and we just don't know how much time we have left."

# Macular Degeneration and Nutritional Research

Patients with advanced cases of dry age-related macular degeneration (AMD) can moderately lower the risk of developing the more severe wet form of the disease and preserve vision by taking a daily dose of antioxidant vitamins and zinc. This finding is the result of the Age-Related Eye Disease Study (AREDS), a randomized, placebo-controlled clinical trial funded by the National Eye Institute. AREDS evaluated over 3600 men and women between the ages of 55 and 80 for an average of 6.3 years.

Dr. Paul Sieving, Director of the National Eye Institute, stated, "Now that we know antioxidants and zinc are helpful in reducing the risk of severe disease, it is even more important for older-age Americans to have regular eye exams. Intervening in at-risk individuals could help reduce severe disease and vision loss in millions of Americans."

Specifically, the AREDS study found that AMD patients with advanced cases of dry AMD or vision loss due to wet AMD in one eye, who took daily supplements containing specified amounts of vitamin C, vitamin E, beta carotene, and zinc, had a 20% chance of developing wet macular degeneration over a five-year period. By comparison, the control group taking a placebo pill lacking any nutrients had a 28% chance of developing wet macular degeneration over a five-year period.

This is the first therapy for patients with advanced cases of dry AMD who are at an increased risk of developing wet AMD. Delaying the onset of wet AMD and its accompanying vision loss by several years can prolong the independence and mobility of seniors and preserve their quality of life.

# The Kelly Family

## Living with macular degeneration

For years, Janet Kelly knew that her family had a history of "bad" eyes. Her dad was legally blind by the time he was 60 and sadly, was forced to leave his job. Two of her aunts also had serious vision problems. In fact, Janet herself always had extremely poor eyesight and has worn glasses for as long as she can remember. But it wasn't until Janet brought her three-year-old son John to an eye specialist 33 years ago that she first heard of macular degeneration. Janet sat in disbelief as she learned that both she and her son had Best disease, an early-onset form of macular degeneration that causes loss of central vision and often results in legal blindness. "I was a wreck when I left the doctor," says Janet, "my heart was aching for my little boy. When I learned that the disease is inherited, somehow I felt responsible."

Although John, now 36, was diagnosed when he was just a child, for most of his life he managed not to make his disease a significant issue. He excelled during high school and college even though he often had trouble seeing the blackboard. Always a natural athlete, John was a gifted lacrosse and football player—although focusing on the ball was sometimes difficult. But in 1995, something happened. His right eye suddenly deteriorated and doctors gave him a grim prognosis. John found himself looking for answers to difficult questions. After a lot of soul searching, John, a man of strong faith, decided not to let his disease get the best of him. That same year, he got involved with Sail For Sight, a Baltimore-based fundraising event benefiting FFB. Thanks to John's efforts, revenue for the event tripled.

While John was learning to move on with his life, unfortunately Best disease was not through with the Kellys. Two years ago, John learned that his five-year-old son Johnny had Best. Then, John's nephew David was diagnosed. "Hearing about my son and nephew was painful," says John. "I didn't want them to go through the hardships that I went through. But thankfully, right now they are happy kids that don't focus on their disease."

While John and his family continue to face many challenges, they are hopeful about the future. "After reading about the dog whose vision was restored through gene therapy," says Janet, "I was excited about what might be around the corner for all retinal degenerative diseases. It is a very encouraging time." John shares his mother's optimism. "I feel confident that through the work of The Foundation and by moving research to clinical trials, a cure could be very close at hand," says John. "I have great hopes that it will happen in time for my son and my nephew, and who knows, it might even happen in time for me and my Mom. All I know is that I want Johnny and David to be the last generation of Kellys that will ever have to face this disease again."

John Kelly with his mom Janet and son Johnny

# A Message from Our Chief Scientific Officer, Dr. Gerald J. Chader

**Drug Delivery: Trojan Horses** Foundation researchers have discovered several promising pharmaceutical agents that dramatically slow vision loss in animal models with retinal degeneration. However, because the retina is protected from the blood supply, traditional systemic delivery methods, such as pills or injections, cannot reach these diseases. As part of its Medical Therapy Program, The Foundation is working with biotechnology companies (profiled below) to develop and test innovative drug delivery devices that, like Trojan Horses, can slip past the retina's defenses to fight these diseases.

Neurotech, a small biotechnology company, has developed an implantable drug delivery device called "encapsulated cell therapy" or ECT. The ECT device consists of a tiny porous capsule containing genetically modified cells. In a unique collaboration, Neurotech and The Foundation found that the ECT device, containing cells that produce a survival factor called ciliary neurotrophic factor (CNTF), slowed vision loss in animal models. Recently, members of The Foundation's scientific advisory board met with Neurotech to offer guidance in helping Neurotech prepare an application to the U.S. Food and Drug Administration to begin clinical trials.

Control Delivery Systems (CDS) has also developed an implantable system that allows for sustained release of drugs to the retina. Smaller than a pencil point, the Envision TD™ system is implanted in the vitreous, the clear gelatinous fluid inside the eye. The device (pictured on the opposite page) encases the drug within a series of permeable layers that allow the drug to slowly diffuse to the retina. CDS hopes to begin clinical trials with this device for a variety of eye diseases.

Implantable drug delivery device developed by Control Delivery Systems

Oculex Pharmaceuticals has developed implantable, biodegradable drug delivery (BDD™) technology for slow release of drugs to treat eye conditions. The Foundation and Oculex are jointly funding a laboratory research project to test the BDD™ system with a steroid to prevent immune response complications after retinal cell transplantation.

IOMED has developed the OcuPhor™ System, which uses very low doses of electrical current to deliver medication to the eye. This device contains an electrode wired to a battery-powered drug dose controller. Placed under the lower eyelid, the electrode transmits small electrical pulses that disperse the drug to the retina. The OcuPhor™ System does not require invasive surgery to implant the device or deliver the drug.

These modern day Trojan Horses could break the barriers to clinical trials, allowing us to test a variety of promising drugs.

Gerald J. Chader

Gerald J. Chader, Ph.D, M.D.,hc

chief scientific officer

# Restoring Vision Through Computer Chips

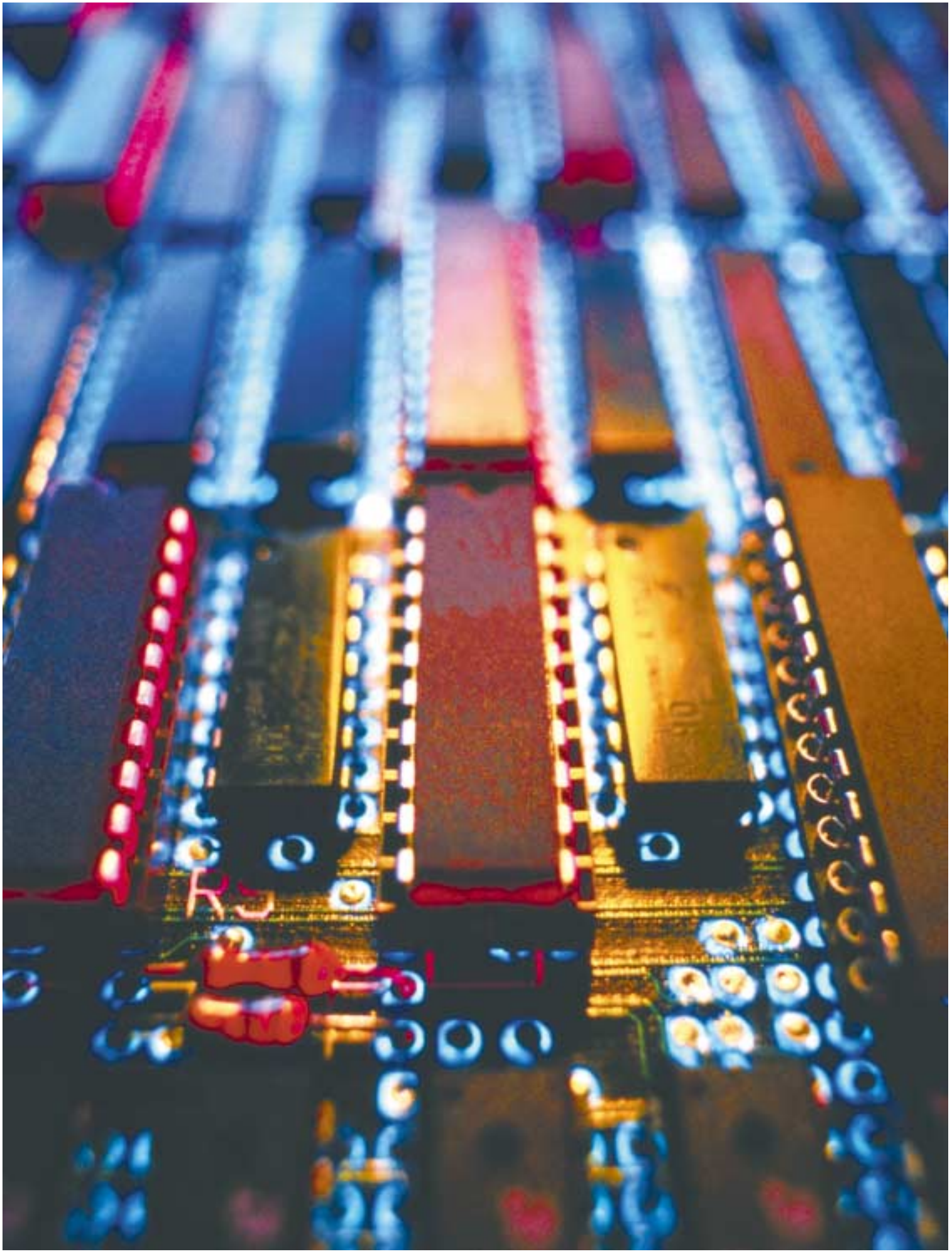
Vision researchers are developing high-tech prosthetic devices that can be surgically implanted in the brain or in the retina to partially restore lost vision to people who are blind. Although highly experimental, these devices might one day restore ambulatory vision, giving people the freedom to walk without the assistance of a cane or guide dog.

Sub-retinal Implants Optobionics, a private company based in Chicago, has begun the first-ever clinical trial to test the safety of their Artificial Silicon Retina (ASR) device in humans. Implanted beneath the retina, the ASR is an example of a sub-retinal implant. The ASR device contains approximately 3500 microscopic solar cells that receive and transmit light. It is completely self-contained and receives its power entirely from the light that enters the eye, requiring no external cameras, wires or power supplies to produce an image. Researchers in Germany are developing a sub-retinal implant with a power supply that amplifies the chip's electronic signal.

Epi-retinal Implants Other groups are developing devices, collectively known as epi-retinal implants, to be implanted on the surface of the retina. These devices receive signals from a camera mounted on a pair of glasses. The signals are then amplified by a power supply. Epi-retinal implants must be affixed to the surface of the retina in order to stay in place. Various research groups are evaluating the safety and effectiveness of surgical tacks and adhesives. Because these devices are complex, they require stringent pre-clinical studies to insure that they can be safely implanted in humans. The Foundation currently supports two groups developing epi-retinal implants: Drs. Eugene de Juan and Mark Humayun at the University of Southern California and Drs. Joseph Rizzo and John Wyatt of Harvard Medical School and Massachusetts Institute of Technology, respectively.

Cortical Implants Dr. Richard Normann, a researcher from the University of Utah, and researchers from the Illinois Institute of Technology are developing cortical implant devices that bypass the diseased retina transmitting images directly to the visual cortex of the brain. These devices must be implanted deep within the visual cortex to reach the neurons that process visual information. Currently, researchers are evaluating surgical techniques that can safely penetrate the visual cortex.

Depending on their complexities, some of these experimental devices will advance to phase 1 human safety studies sooner than others. Once clinical trials begin, researchers can begin to test the safety and effectiveness of these devices in real world conditions.



RESTORING VISION 2001

GENE THERAPY

# Research Grants

STEM CELL RESEARCH

PREVENTION

TRANSPLANTATION

BIOTECHNOLOGY

PHARMACEUTICAL THERAPIES

GENE MUTATION

VISION RESEARCH

MOMENTUM

DISCOVERY OF CAUSES

July 1, 2000 to June 30, 2001 Fiscal Year

## Research Center Grants

### Berman-Gund Laboratory for the Study of Retinal Degenerative Diseases
**$329,111**
Harvard Medical School
Massachusetts Eye and Ear Infirmary
Boston, MA
Eliot L. Berson, M.D., Center Coordinator

### The Cleveland Clinic Foundation Research Center for the Study of Retinal Degenerative Diseases
**$289,956**
Cleveland, OH
Joe G. Hollyfield, Ph.D., Center Coordinator

### Emory University Research Center for the Study of Retinal Degenerative Diseases
**$206,124**
Emory University
School of Medicine
Atlanta, GA
Paul Sternberg, M.D., Center Coordinator

### Research Center for the Study of Macular Degeneration and Allied Retinal Diseases
**$343,200**
University of Iowa
Iowa City, IA
Edwin M. Stone, M.D., Ph.D., Center Coordinator

### Research Center for the Study of Retinal Degenerative Diseases at the Jules Stein Eye Institute
**$330,991**
The University of California at Los Angeles (UCLA)
Los Angeles, CA
Dean Bok, Ph.D., Center Coordinator

### The Kearn Family Research Center for the Study of Retinal Degeneration
**$331,260**
Beckman Vision Center
Kearn Family Research Center
University of California at San Francisco
San Francisco, CA
Matthew M. LaVail, Ph.D., Center Coordinator

### Michael M. Wynn Center for Inherited Retinal Degenerative Diseases at the University of Utah
**$279,140**
Moran Eye Center
University of Utah
Health Sciences Center
Salt Lake City, UT
Wolfgang Baehr, Ph.D., Center Coordinator

### The Research Center for the Study of Retinal Degenerative Diseases at The New York University Medical Center
**$113,417**
Department of Ophthalmology
New York, NY
Ronald E. Carr, M.D., Center Coordinator

### The Research Center for the Study of Retinal Degenerative Diseases at The Oregon Health Sciences University
**$180,697**
Department of Ophthalmology
Portland, OR
Richard G. Weleber, M.D., Center Coordinator

### Pre-Clinical Medical Therapy Evaluation Center
**$563,393**
Cornell University, Ithaca, NY
North Carolina State University, Raleigh, NC
Duke University, Durham, NC
Gustavo Aguirre, Ph.D., Center Coordinator

### Scandinavian Research Center for the Study of Retinal Degenerative Diseases
**$259,800**
Department of Ophthalmology
Lund, Sweden
Berndt Ehinger, M.D., Center Coordinator

### Research Center for the Study of Retinal Degenerative Diseases at the Scheie Eye Institute
**$392,601**
University of Pennsylvania
Philadelphia, PA
Samuel G. Jacobson, M.D., Ph.D., Center Coordinator

Southwest Regional Research Center for the Study of Retinal Degenerative Diseases
**$412,982**
Retina Foundation of Southwest, Dallas, TX
University of Texas, Dallas, TX
University of Oklahoma, Oklahoma City, OK
University of Texas, Houston, TX
Robert E. Anderson, M.D. and David Birch, Ph.D., Center Co-Coordinators

Research Center for the Study of Retinal Degenerative Diseases at the University of Illinois Eye & Ear Infirmary
**$133,922**
Chicago, IL
Gerald A. Fishman, M.D., Center Coordinator

Research Center at the Institute of Ophthalmology
**$303,298**
London and Moorfields Eye Hospital
London, England
Frederick W. Fitzke, Ph.D., Center Coordinator

Research Center for the Study of Retinal Degenerative Diseases and AMD at the Wilmer Eye Institute
**$645,901**
Ophthalmology Department
Johns Hopkins Hospital
Baltimore, MD
Peter A. Campochiaro, M.D., Center Coordinator

Research Center for the Study of Retinal Degenerative Diseases at the W.K. Kellogg Eye Center
**$414,123**
University of Michigan
Ann Arbor, MI
Paul A. Sieving, M.D., Ph.D., Center Coordinator

## Research Facility

The FFB Retinal Degeneration Histopathology Facility at the Scheie Eye Institute
**$81,431**
University of Pennsylvania
Philadelphia, PA
Ann Milam, Ph.D., Facility Coordinator

## Individual Grants

### CELL BIOLOGY

Muayyard R. Al-Ubaidi, Ph.D.
**$70,000**
University of Oklahoma Health Sciences Center
Oklahoma City, OK

Beth Burnside, Ph.D.
**$54,182**
University of California
Berkeley, CA

M. Carter Cornwall, Ph.D.
**$18,300**
Boston University School of Medicine
Boston, MA

Frans P. M. Cremers, Ph.D. and A.I. den Hollander
**$59,481**
University Hospital Nijmegen
Netherlands

Leonard M. Hjelmeland, Ph.D.
**$44,460**
University of California
Davis, CA

Gerard A. Lutty, Ph.D.
**$92,880**
Wilmer Eye Institute
Johns Hopkins University
Baltimore, MD

Jian-xing Ma, M.D., Ph.D. and Rosalie K. Crouch, Ph.D.
**$74,500**
Medical University of South Carolina
Charleston, SC

Judith Mosinger-Ogilvie, Ph.D.
**$67,260**
Central Institute for the Deaf
St. Louis, MO

Jeremy Nathans, M.D., Ph.D.
**$50,545**
Johns Hopkins University School of Medicine
Baltimore, MD

David S. Papermaster, M.D.
**$55,400**
University of Connecticut
Farmington, CT

Ching-Hwa Sung, Ph.D.
**$28,282**
Cornell University
New York, NY

Debra A. Thompson, Ph.D.
**$75,000**
University of Michigan Medical School
Ann Arbor, MI

Frederik J.G.M. van Kuijk
**$48,161**
University of Texas Medical Branch
Galveston, TX

David S. Williams, Ph.D.
**$66,349**
UCSD School of Medicine
La Jolla, CA

Fulton Wong, Ph.D.
**$72,100**
Duke University Medical Center
Durham, NC

Marco A. Zarbin, M.D.
**$81,271**
UMDNJ - New Jersey
Medical School
Newark, NJ

## CLINICAL STUDIES

Joan W. Miller, M.D.
**$49,195**
Harvard Medical School
Massachusetts Eye and Ear
Infirmary
Boston, MA

Johanna Seddon, M.D. (2 grants)
**$111,200**
Harvard Medical School
Massachusetts Eye and Ear
Infirmary
Boston, MA

## DRUG DELIVERY

Dayle H. Geroski, Ph.D., Henry F. Edelhauser, Ph.D.
**$43,338**
Emory University Eye Center
Atlanta, GA

Mark Saltzman, Ph.D.
**$59,354**
Cornell University
Ithaca, NY

Homayoun Tabandeh, M.D. and William Hauswirth, Ph.D.
**$46,250**
University of Florida
College of Medicine
Gainesville, FL

Marco A. Zarbin, M.D., Ph.D.
**$103,334**
UMDNJ –New Jersey
Medical School
Newark, NJ

## GENE THERAPY

Stephen P. Goff, Ph.D.
**$71,620**
Howard Hughes Medical Institute
Columbia University
New York, NY

William W. Hauswirth, Ph.D. and Alfred S. Lewin, Ph.D.
**$71,946**
University of Florida
College of Medicine
Gainesville, FL

Robert G. Korneluk, Ph.D.
**$58,174**
University of Ottawa and
Children's Hospital of
Eastern Ontario

Alfred Lewin, Ph.D.
**$18,362**
University of Florida
College of Medicine
Gainesville, FL

Tiansen Li, Ph.D.
**$58,496**
Harvard Medical School
Massachusetts Eye and Ear
Infirmary
Boston, MA

Muna I. Naash, Ph.D. (2 grants)
**$87,132**
University of Oklahoma
Health Science Center
Oklahoma City, OK

Kristina Narfstrom, D.V.M., Ph.D.
**$91,000**
University of Missouri
Columbia, MO

Adrian M. Timmers, Ph.D.
**$53,348**
University of Florida
College of Medicine
Gainesville, FL

## GENETICS STUDIES

Arthur A. B. Bergen, Ph.D. and Paulus de Jong, M.D., Ph.D.
**$37,000**
Netherlands Ophthalmic Research
Institute
Amsterdam, The Netherlands

W. Berger, Ph.D.
**$66,920**
Max-Planck Institute for
Molecular Genetics
Berlin, Germany

Shomi S. Bhattacharya, Ph.D.
**$69,836**
Institute of Ophthalmology
London, England

F.P.M. Cremers, Ph.D. and C. B. Hoyng, Ph.D., A.F. Deutman, M.D., Ph.D.
**$68,224**
University Hospital, Nijmegen
Netherlands

Michael Danciger, Ph.D. and Debora B. Farber, Ph.D.
**$62,040**
Jules Stein Eye Institute, UCLA
Los Angeles, CA

Michael J. Denton, Ph.D.
**$33,103**
University of Otago
Dunedin, New Zealand

Thaddeus Dryja, M.D.
**$74,278**
Harvard Medical School
Massachusetts Eye and Ear
Infirmary
Boston, MA

Debora Farber, Ph.D. and Michael Danciger, Ph.D.
**$73,110**
Jules Stein Eye Institute, UCLA
Los Angeles, CA

Andreas Gal, M.D., Ph.D.
**$73,130**
University Hospital Eppendorf
Hamburg, Germany

Peter Humphries, Ph.D.
**$56,251**
Trinity College
Dublin, Ireland

George Inana, Ph.D.
**$73,357**
University of Miami
Miami, FL

Josselin Kaplan, M.D.
**$72,100**
Hopital Necker-Enfants Malades
Paris, France

Bronya Keats, Ph.D.
**$53,766**
LSU Medical Center
New Orleans, LA

William Kimberling, Ph.D.
**$77,323**
Boys Town
National Research Hospital
Omaha, NE

James Lupski, M.D., Ph.D. and Richard Lewis, M.D.
**$72,899**
Baylor College
Houston, TX

Patsy M. Nishina, Ph.D.
**$65,510**
The Jackson Laboratory
Bar Harbor, ME

Eric Pierce, M.D., Ph.D.
**$60,212**
Scheie Eye Institute
University of Pennsylvania
Philadelphia, PA

Steven J. Pittler, Ph.D.
(2 grants)
**$138,578**
University of Alabama
at Birmingham
Birmingham, AL

Edwin M. Stone, M.D., Ph.D.
**$72,100**
University of Iowa Hospitals
Iowa City, IA

Anand Swaroop, Ph.D.
**$103,942**
University of Michigan
Ann Arbor, MI

## PHARMACEUTICAL THERAPY

Thomas A. Ferguson, Ph.D.
**$51,016**
Washington University
St. Louis, MO

David Hicks, Ph.D.
**$69,181**
University of British Columbia
Vancouver B.C., Canada

Thomas Reh, Ph.D.
**$67,154**
University of Washington
Seattle, WA

Jose A. Sahel, M.D.
**$58,150**
Universite Louis Pasteur
Strasbourg, France

Toshimichi Shinohara, Ph.D.
**$60,224**
Brigham and Women's Hospital
Boston, MA

Paul Sieving, M.D., Ph.D.
**$219,857**
W. K. Kellogg Eye Center
University of Michigan
Medical Center
Ann Arbor, MI

## PRE-CLINICAL STUDIES

Bo Chang, M.D.
**$58,872**
The Jackson Laboratory
Bar Harbor, ME

Muriel T. Davisson, Ph.D.
(2 grants)
**$65,703**
The Jackson Laboratory
Bar Harbor, ME

David R. Hyde, Ph.D.
**$74,260**
University of Notre Dame
Notre Dame, IN

Janis Lem, Ph.D.
**$54,080**
Tufts University, New England
Medical Center
Boston, MA

Miguel C. Seabra, M.D., Ph.D.
**$79,176**
Imperial College
London, England

David S. Williams, Ph.D.
**$78,597**
UCSD School of Medicine
La Jolla, CA

Alan F. Wright, Ph.D.
**$71,693**
Western General Hospital
Edinburgh, Scotland

## SURGERY AND VISUAL PROSTHETICS

Eugene de Juan, Jr., M.D.
**$28,404**
Wilmer Eye Institute
Johns Hopkins University
Baltimore, MD

Joseph F. Rizzo, M.D.
**$79,495**
Harvard Medical School
Massachusetts Eye and Ear
Infirmary
Boston, MA

## TRANSPLANTATION STUDIES

Iqbal Ahmad, Ph.D.
**$66,813**
University of Nebraska
Medical Center
Omaha, NE

Robert B. Aramant, Ph.D.
**$104,240**
University of Louisville
School of Medicine
Louisville, KY

Lucian Del Priore, M.D., Ph.D.
**$73,731**
Edward S. Harkness Eye Institute
New York, NY

Derek van der Kooy, Ph.D.
**$64,863**
University of Toronto
Ontario, Canada

## CAREER DEVELOPMENT AWARDS

Tomas Aleman, M.D.
**$50,000**
Scheie Eye Institute
University of Pennsylvania
Philadelphia, PA

Jayakrishna Ambati, M.D.
**$24,569**
Harvard Medical School
Massachusetts Eye and Ear
Infirmary
Boston, MA

Adriana Di Polo, Ph.D.
**$41,582**
University of Montreal
Montreal, Quebec, Canada

Albert O. Edwards, M.D., Ph.D.
**$50,000**
University of Texas
Dallas, TX

Deborah A. Ferrington, Ph.D.
**$12,500**
University of Minnesota
Minneapolis, MN

Mark S. Humayun, M.D., Ph.D.
**$57,800**
Wilmer Eye Institute
Johns Hopkins University
Baltimore, MD

Shalesh Kaushal, M.D., Ph.D.
**$50,000**
University of Minneapolis
Minneapolis, MN

Xue Zhong Liu, M.D., Ph.D.
**$69,450**
Medical College of Virginia/VCU
Richmond, VA

Kean T. Oh, Ph.D.
**$50,000**
University of North Carolina at
Chapel Hill
Chapel Hill, NC

Vassiliki Poulaki, M.D.
**$12,500**
Harvard Medical School
Massachusetts Eye and Ear
Infirmary
Boston, MA

Dennis W. Schultz, Ph.D.
**$60,253**
Oregon Health Sciences Univ.
Casey Eye Institute
Portland, OR

Stephen Tsang, M.D., Ph.D.
**$73,687**
Jules Stein Eye Institute, UCLA
Los Angeles, CA

## OTHER GRANTS:

## SPECIAL EQUIPMENT

Gustavo Aguirre, Ph.D., V.M.D.
& Gregory M. Acland, B.V.Sc.
**$68,000**
ERG Equipment for Dog Colony

Gregory Hageman, Ph.D.
**$44,985**
University of Iowa
Iowa City, IA
Luminex 100 Total System
Machine

## MEETINGS

RP1 Consortium Meeting
**$5,000**

European Union Meeting
**$25,000**
July 13-15, 2001
Prague, Czech Republic
"New Therapeutic Approaches in
Hereditary Eye Disease:
From Genes to a Cure"

Clinical and Experimental
Aspects of Transplantation
Approaches for Inherited
Retinal Degenerative Diseases
**$20,000**
June 20-22, 2002
University of Utah

Neuroprotection Treatment
Strategies for Retinal
Degeneration
**$38,000**
September 6-10, 2002
University of Lund, Sweden,

## BOARD OF TRUSTEE AWARDS

Samuel G. Jacobson, M.D.,
Ph.D. and Krzysztof
Palczewski, Ph.D.
**$25,000**

## LLURA LIGGETT GUND AWARD

John E. Dowling, Ph.D.
**$22,000**
Harvard University

# Financial Information
# Table of Contents


27 Report of Independent Accountants

Consolidated Financial Statements

28 Consolidated Statement of Financial Position

29 Consolidated Statement of Activities

30 Consolidated Statement of Functional Expenses

32 Consolidated Statement of Cash Flows

33 Notes to Consolidated Financial Statements

# Report of Independent Accountants

To the Board of Trustees of
The Foundation Fighting Blindness, Inc.:

In our opinion, the accompanying consolidated statement of financial position and the related statements of activities and changes in net assets, cash flows, and expenses by function present fairly, in all material respects, the financial position of The Foundation Fighting Blindness and its affiliated chapters ("The Foundation") at June 30, 2001, and the consolidated changes in their net assets and their cash flows for the year then ended in conformity with accounting principles generally accepted in the United States of America. These financial statements are the responsibility of The Foundation's management; our responsibility is to express an opinion on these financial statements based on our audit. The prior year summarized comparative information has been derived from The Foundation's June 30, 2000 financial statements, and in our report dated September 22, 2000, we expressed an unqualified opinion on those financial statements. We conducted our audit of these statements in accordance with auditing standards generally accepted in the United States of America, which require that we plan and perform the audit to obtain reasonable assurance about whether the financial statements are free of material misstatement. An audit includes examining, on a test basis, evidence supporting the amounts and disclosures in the financial statements, assessing the accounting principles used and significant estimates made by management, and evaluating the overall financial statement presentation. We believe that our audit provides a reasonable basis for our opinion.

October 2, 2001

# Consolidated Statement of Financial Position

as of June 30, 2001 (with summarized financial information for the year ended June 30, 2000)

| | 2001 | | | | 2000 |
|---|---|---|---|---|---|
| | Unrestricted | Temporarily Restricted | Permanently Restricted | Total | Total |
| **Assets** | | | | | |
| Cash and cash equivalents | $ 4,046,095 | $ — | $ — | $ 4,046,095 | $ 4,698,698 |
| Investments | 3,084,636 | 73,819 | 500,000 | 3,658,455 | 2,794,933 |
| Pledges receivable, net of present value allowance of $52,644 in 2001 ($92,820 in 2000) | 908,883 | 1,888,570 | | — | 2,216,453 |
| Accrued interest and prepaid expenses | 195,317 | — | — | 2,797,453<br>195,317 | 214,331 |
| Pooled income fund | — | 84,271 | — | 84,271 | 46,967 |
| Charitable remainder trust | — | 875,826 | — | 875,826 | 708,029 |
| Fixed assets, net | 886,803 | — | — | 886,803 | 754,268 |
| Total assets | $ 9,121,734 | $ 2,922,486 | $ 500,000 | $12,544,220 | $11,433,679 |
| **Liabilities and Net Assets** | | | | | |
| Accounts payable and accrued expenses | $ 1,072,176 | $ — | $ — | — | $ 774,098 |
| Research awards and grants payable | 6,259,681 | — | — | $ 1,072,176<br>6,259,681 | 5,081,529 |
| Deferred revenue | 164,689 | — | — | 164,689 | 339,776 |
| Pooled income fund obligation | — | 42,498 | — | 42,498 | 24,824 |
| Charitable remainder trust obligation | — | 399,918 | — | 399,918 | 339,973 |
| Total liabilities | $ 7,496,546 | 442,416 | — | 7,938,962 | 6,560,200 |
| **Net assets** | | | | | |
| Unrestricted net assets: | | | | | |
| Designated for research | 738,385 | — | — | 738,385 | 1,409,092 |
| Represented by fixed assets | 886,803 | — | — | 886,803 | 754,268 |
| Total unrestricted net assets | 1,625,188 | — | — | 1,625,188 | 2,163,360 |
| Temporarily restricted net assets | — | 2,480,070 | — | 2,480,070 | 2,214,179 |
| Permanently restricted net assets | — | — | 500,000 | 500,000 | 495,940 |
| Total net assets | 1,625,188 | 2,480,070 | 500,000 | 4,605,258 | 4,873,479 |
| Total liabilities and net assets | $ 9,121,734 | $ 2,922,486 | $ 500,000 | $12,544,220 | $11,433,679 |



The accompanying notes are an integral part of these consolidated financial statements

# Consolidated Statement of Activities

as of June 30, 2001 (with summarized financial information for the year ended June 30, 2000)

| | 2001 | | | | 2000 |
|---|---|---|---|---|---|
| | Unrestricted | Temporarily Restricted | Permanently Restricted | Total | Total |
| **Revenues** | | | | | |
| Public support: Contributions from individuals, corporations and foundations | $ 5,069,261 | $ 5,388,029 | $ 797 | $ 10,458,087 | $ 11,969,458 |
| Special events | 6,592,526 | — | — | 6,592,526 | 5,229,382 |
| Less special event direct benefit costs | (1,781,717) | — | — | (1,781,717) | (1,824,272) |
| Legacies and bequests | 2,015,852 | — | 3,263 | 2,019,115 | 1,634,904 |
| Allocated by federated fundraising organizations | 154,489 | — | — | 154,489 | 117,262 |
| Contributed services | 40,812 | — | — | 40,812 | 31,564 |
| Total public support | 12,091,223 | 5,388,029 | 4,060 | 17,483,312 | 17,158,298 |
| **Other** | | | | | |
| Program service fees | 101,755 | — | — | 101,755 | 108,178 |
| Investment and other income | 427,389 | 25,772 | — | 453,161 | 383,716 |
| Net assets released from restrictions: Satisfaction of program restrictions | 5,147,910 | (5,147,910) | — | — | — |
| Total revenue and other support | 17,768,277 | 265,891 | 4,060 | 18,038,228 | 17,650,192 |
| **Expenses** | | | | | |
| Program services: | | | | | |
| Research | 12,532,256 | — | — | 12,532,256 | 11,803,326 |
| Public health education | 937,106 | — | — | 937,106 | 1,080,438 |
| Human services | 876,443 | — | — | 876,443 | 550,299 |
| Total program services | 14,345,805 | — | — | 14,345,805 | 13,434,063 |
| **Supporting Services** | | | | | |
| Management and general | 1,208,354 | — | — | 1,208,354 | 1,163,354 |
| Fundraising | 2,752,290 | — | — | 2,752,290 | 2,429,690 |
| Total supporting services | 3,960,644 | — | — | 3,960,644 | 3,593,044 |
| Total expenses | 18,306,449 | — | — | 18,306,449 | 17,027,107 |
| **Change in net assets** | (538,172) | 265,891 | 4,060 | (268,221) | 623,085 |
| Net assets at beginning of year | 2,163,360 | 2,214,179 | 495,940 | 4,873,479 | 4,250,394 |
| Net assets at end of year | $ 1,625,188 | $ 2,480,070 | $ 500,000 | $ 4,605,258 | $ 4,873,479 |

The accompanying notes are an integral part of these consolidated financial statements

# Consolidated Statement of Functional Expenses

for the year ended June 30, 2001 (with summarized financial information for the year ended June 30, 2000)

| | PROGRAM SERVICES 2001 | | | |
|---|---|---|---|---|
| | Research | Public Health Education | Human Services | Total |
| Salaries | $ 730,899 | $ 397,290 | $ 291,577 | $ 1,419,766 |
| Employee health and retirement benefits | 75,352 | 40,122 | 38,318 | 153,792 |
| Payroll taxes | 46,491 | 27,353 | 20,786 | 94,630 |
| Total salaries and related expenses | 852,742 | 464,765 | 350,681 | 1,668,188 |
| Professional fees | 173,364 | 59,632 | 43,604 | 276,600 |
| Supplies | 22,031 | 23,957 | 38,731 | 84,719 |
| Telecommunications | 14,419 | 18,453 | 18,746 | 51,618 |
| Postage | 5,297 | 20,066 | 128,773 | 154,136 |
| Occupancy | 52,057 | 35,936 | 22,216 | 110,209 |
| Rental and maintenance of equipment | 26,790 | 11,491 | 12,682 | 50,963 |
| Printing and publications | 13,436 | 54,863 | 132,015 | 200,314 |
| Travel, conferences and meetings | 150,077 | 80,920 | 12,562 | 243,559 |
| National conference | — | 126,439 | 85,550 | 211,989 |
| Membership dues | 36,989 | 2,697 | 3,208 | 42,894 |
| Insurance | 15,849 | 10,490 | 6,724 | 33,063 |
| Miscellaneous | 8,128 | 8,063 | 7,993 | 24,184 |
| Depreciation and amortization | 82,225 | 19,334 | 12,958 | 114,517 |
| Total expenses before grants and awards | 1,453,404 | 937,106 | 876,443 | 3,266,953 |
| Grants and awards | 11,078,852 | — | — | 11,078,852 |
| Total expenses | $12,532,256 | $ 937,106 | $ 876,443 | $14,345,805 |
| Special event direct benefit costs | | | | |
| Total expenses and special event direct benefit cost | | | | |

| SUPPORTING SERVICES 2001 | | | TOTAL EXPENSES | |
|---|---|---|---|---|
| Management and General | Fundraising | Total | 2001 | 2000 |
| $ 602,955 | $1,518,144 | $ 2,121,099 | $ 3,540,865 | $ 3,050,660 |
| 74,994 | 160,843 | 235,837 | 389,629 | 321,660 |
| 41,238 | 109,594 | 150,832 | 245,462 | 205,942 |
| 719,187 | 1,788,581 | 2,507,768 | 4,175,956 | 3,578,262 |
| 87,898 | 123,918 | 211,816 | 488,416 | 547,718 |
| 51,667 | 92,727 | 144,394 | 229,113 | 186,040 |
| 26,106 | 80,994 | 107,100 | 158,718 | 168,126 |
| 13,088 | 103,903 | 116,991 | 271,127 | 258,699 |
| 46,797 | 123,385 | 170,182 | 280,391 | 201,462 |
| 28,346 | 49,035 | 77,381 | 128,344 | 72,660 |
| 37,193 | 142,820 | 180,013 | 380,327 | 481,328 |
| 89,464 | 148,932 | 238,396 | 481,955 | 472,130 |
| — | — | — | 211,989 | 256,033 |
| 1,145 | 2,510 | 3,655 | 46,549 | 29,583 |
| 13,664 | 35,991 | 49,655 | 82,718 | 82,511 |
| 70,141 | 14,216 | 84,357 | 108,541 | 28,769 |
| 23,658 | 45,278 | 68,936 | 183,453 | 172,773 |
| 1,208,354 | 2,752,290 | 3,960,644 | 7,227,597 | 6,536,094 |
| — | — | — | 11,078,852 | 10,491,013 |
| $ 1,208,354 | $ 2,752,290 | $ 3,960,644 | 18,306,449 | 17,027,107 |
| | | | 1,781,717 | 1,824,272 |
| | | | $20,088,166 | $18,851,379 |

The accompanying notes are an integral part of these consolidated financial statements

# Consolidated Statement of Cash Flows

for the years ended June 30, 2001 and 2000

| | 2001 | 2000 |
|---|---|---|
| **Reconciliation of changes in net assets to net cash used by operating activities:** | | |
| Change in net assets | $ (268,221) | $ 623,085 |
| Adjustments to reconcile net assets to cash provided by operating activities: | | |
| Depreciation and amortization | 183,453 | 172,773 |
| Loss on disposal of equipment | 21,935 | 133 |
| Contributions to pooled income fund | (19,631) | (5,779) |
| Contributions to charitable remainder trust | (107,851) | (246,745) |
| Contributions restricted for long-term investment | (4,060) | (495,940) |
| Changes in assets and liabilities: | | |
| Pledges receivables | (581,000) | (1,062,081) |
| Prepaid expenses and other receivables | 19,014 | (37,670) |
| Accounts payable and accrued expenses | 298,078 | 22,716 |
| Research awards and grants payable | 1,178,152 | 30,697 |
| Deferred revenue | (175,087) | 200,304 |
| Net cash provided by operating activities | 544,782 | (798,507) |
| **Cash flows from investing activities:** | | |
| Purchases of investment securities | (11,084,493) | (8,638,548) |
| Proceeds from sales of investment securities | 10,220,971 | 11,167,634 |
| Purchase of pooled income and charitable remainder trust securities | (126,170) | (234,054) |
| Proceeds from sales of pooled income and charitable remainder trust securities | 48,551 | 33,214 |
| Purchase of equipment | (337,923) | (62,135) |
| Net cash (used in) provided by investing activities | (1,279,064) | 2,266,111 |
| **Cash flows from financing activities:** | | |
| Proceeds from contributions restricted for investment in endowment | 4,060 | 495,940 |
| Liability related to pooled income fund | 20,793 | 12,010 |
| Payments to pooled income fund beneficiaries | (3,119) | (1,936) |
| Liability related to charitable remainder trust | 105,377 | 222,044 |
| Payments to charitable remainder trust beneficiaries | (45,432) | (31,278) |
| Net cash used in financing activities | 81,679 | 696,780 |
| Net increase in cash and cash equivalents | (652,603) | 2,164,384 |
| Cash and cash equivalents, beginning of period | 4,698,698 | 2,534,314 |
| Cash and cash equivalents, end of period | $ 4,046,095 | $ 4,698,698 |
| Supplemental disclosures of cash flow information | | |
| Receipt of stock gifts | $ 2,429,941 | $ 2,221,727 |



The accompanying notes are an integral part of these consolidated financial statements

# Notes to Consolidated Financial Statements

## 1. Summary of Significant Accounting Policies

### Nature of Operations

The Foundation Fighting Blindness, Inc. and its affiliated chapters ("The Foundation") is a national eye research foundation which raises money to fund laboratory and clinical research at prominent institutions in the United States and foreign countries for the discovery of the causes, treatments, preventative methods, and cures, for all retinal degenerative eye diseases which include retinitis pigmentosa, macular degeneration and Usher syndrome. The Foundation also serves as a source of information for professionals and affected families. Its principal programs include:

Research - The Foundation funds research in retinal degenerative diseases at research facilities, both nationally and internationally.

Human Services - The Foundation provides human services information relative to lifestyle issues and understanding of the retinal diseases, as well as, physician referral services for those affected.

Public Health Education - The Foundation produces newsletters that provide examples of The Foundation's dedication to finding the cause, treatments, cures, and preventative methods for retinal degenerative diseases.

### Basis of Presentation

The accompanying consolidated financial statements have been prepared in accordance with accounting principles generally accepted in the United States of America applicable to voluntary health and welfare organizations. The Foundation follows Statement of Financial Accounting Standards No. 117, "Financial Statements of Not-for-Profit Organizations" (the "Statement"). This Statement specifies that financial statements provided by not-for-profit organizations include statements of financial position, statements of activities, statement of functional expenses and statements of cash flows. This Statement further provides that net assets be classified as unrestricted, temporarily restricted, or permanently restricted based upon the existence or absence of donor-imposed restrictions.

The consolidated financial statements include the accounts of The Foundation and its affiliated chapters. All material balances and transactions between The Foundation and its affiliated chapters have been eliminated.

The financial statements include certain prior-year summarized comparative information in total but not by net asset class. Such information does not include sufficient detail to constitute a presentation in conformity with accounting principles generally accepted in the United States of America. Accordingly, such information should be read in conjunction with the organization's financial statements for the year ended June 30, 2000, from which the summarized information was derived.

### Classification of Net Assets

The Foundation's consolidated financial statements report amounts separately by class of net assets:

a) Unrestricted Net Assets – Unrestricted net assets result from revenues derived from providing services, receiving unrestricted contributions less expenses incurred in providing services, raising contributions and performing administrative functions. These amounts are available at the discretion of the Board for use in The Foundation's operations including future research and those resources invested in equipment.

## Notes to Consolidated Financial Statements

b) Temporarily Restricted Net Assets – Temporarily restricted net assets result from contributions and other inflows of assets whose use by the organization is limited by donor-imposed stipulations that either expire by passage of time or can be fulfilled and removed by the actions of the Foundation pursuant to those restrictions.

c) Permanently Restricted Net Assets – Permanently restricted net assets are subject to donor-imposed stipulations that they be maintained permanently by the Foundation. The donor of these assets permits The Foundation to use the investment return for research.

Unrealized and realized gains and losses and interest from investing in income producing assets may be included in any of these net asset classifications depending on donor restrictions.

### Recognition of Revenues

Contributions received and unconditional promises to give are measured at their fair market values and are reported as an increase in the appropriate net asset category. All contributions are considered to be available for unrestricted use unless specifically restricted by the donor.

Contributions that are restricted by the donor for a specific time or purpose are reported as temporarily or permanently restricted contributions based on the nature of the restriction. When a donor restriction expires, that is, when a stipulated time restriction ends or purpose of the restriction is accomplished, temporarily restricted net assets are reclassified to unrestricted net assets and are reported in the consolidated statement of activities as net assets released from restrictions. Bequests are recognized at the time an unassailable right to the gift has been established, the proceeds are measurable and the Foundation accepts the gift.

Unconditional promises to give (pledges) that are expected to be collected within one year are recorded at their net realizable value. Unconditional promises to give that are expected to be collected in future years are recorded at the present value of the amounts expected to be collected. Conditional promises to give are not included as support until such time as the conditions are substantially met.

Contributions of equipment without donor stipulations concerning the use of such long-lived assets are reported as revenues of the unrestricted net asset class. Contribution of cash or other assets to be used to acquire equipment without such donor stipulations are reported as revenues of the temporarily restricted net asset class. Temporary restrictions of gifts to acquire long-lived assets are considered met in the period in which the fixed assets are acquired or placed in service.

Net assets are released from donor restrictions by incurring expenses that satisfy the restricted purposes, by the occurrence of events specified by the donors or by the change of restrictions specified by the donors. In 2001, The Foundation released $5,147,911 in temporarily restricted net assets for program use.

### Contributed Services

In accordance with Statement of Financial Accounting Standards (“SFAS”) 116, Accounting for Contributions Received and Contributions Made, only the value of the contributed services that are considered specialized and that can be estimated are reflected in these statements. Contributed services are reported in the consolidated statement of activities at the fair value of the services received. The Foundation received $40,812 and $31,564 of contributed legal services for the years ended June 30, 2001, and 2000, respectively. In addition, services have been provided to the Foundation by unpaid volunteers, however, they did not qualify for inclusion in these statements.

## Notes to Consolidated Financial Statements

### Cash, Cash Equivalents and Investments

Cash and cash equivalents consist of cash held in checking and savings accounts and funds invested overnight in interest bearing accounts at federally insured financial institutions as well as money market accounts held in brokerage accounts not subject to donor restrictions. Cash equivalents are stated at cost, which approximates fair value.

### Investments

Investments consist solely of U.S. Government agency obligations which are stated at fair value, as well as, permanently restricted money market accounts. Bond premiums and discounts are amortized into interest income over the term of the bond.

### Concentration of Credit Risk

Cash is held at certain financial institutions in excess of federally insured amounts. At June 30, 2001 and 2000, $1,681,631, and $2,148,249, respectively, was held at such institutions. The Foundation has not incurred any losses on these funds. The Foundation received approximately 14% and 13% of its total public support from its Board of Trustees in fiscal years 2001 and 2000, respectively.

Approximately 50% and 52% of the pledges receivable at June 30, 2001 and June 30, 2000 are due from two contributors and one contributor, respectively.

### Pooled Income Fund and Charitable Remainder Trust Fund

During fiscal year 1998, The Foundation initiated a Pooled Income Fund (the "Fund"), which enables donors to pool in one trust, gifts of money and other acceptable property for which the creation of individual trust accounts would be impractical. During fiscal year 1999, The Foundation was the recipient of a Charitable Remainder Trust (the "Trust") contributed by a donor. The assets of both the Fund and the Trust are held in trust by a third party trustee and represent resources not in the possession of but under the control of The Foundation.

The donors to the Fund retain the right to receive a portion of the income generated by the Fund's investments during their lifetime or during the lifetime of a beneficiary designated by the donor. The donors to the Trust retain the right to receive an established percentage of the Trust assets during their lifetime or during the lifetime of a beneficiary designated by the donor. Upon termination of the donor agreements, the Fund/Trust principal passes from the Fund/Trust to The Foundation for general use unless stipulated for specific purpose by the donor. The market values of the Fund/Trust assets as well as the related obligations to the beneficiaries are reflected in the consolidated statement of financial position.

Under the standards set forth in the AICPA Guide for Accounting and Auditing of Not-for-Profit Organizations, contribution revenues are recognized at fair market value on the date the fund or trust is established, net of the liabilities for the present value of the estimated future payments to be made to donors and/or other beneficiaries. The liabilities are adjusted during the term of the fund/trust for changes in the value of the assets, accretion of the discount and other changes in the estimates of future benefits. The liability for the present value of deferred gifts is based upon actuarial estimates and assumptions regarding the duration of the agreements and the rates to discount the liability, which was 6% at June 30, 2001 and 8% at June 30, 2000. Circumstances affecting these assumptions can change the estimate of this liability in future periods.

## Notes to Consolidated Financial Statements

### Fixed Assets
All fixed assets are carried at cost and are depreciated on a straight-line basis over the following useful lives:

| | |
|---|---|
| Research facility | 23 years |
| Leasehold improvements | 9 years |
| Furniture, fixtures and equipment | 3-5 years |

Contributions of equipment are recorded at the fair market value at the date of receipt. If donors stipulate the purpose for which the asset must be used and/or how long the asset must be held, the contributions are recorded as temporarily restricted, otherwise such donations are reported as unrestricted. Temporary restrictions of gifts to acquire long-lived assets are considered met in the period in which the fixed assets are acquired or placed in service.

### Accrued Compensation
The Foundation accrues for vacation pay and all other compensation earned but not paid.

### Grants
The Foundation generally awards grants for periods of five years or less. Payment of each grant is contingent upon satisfactory progress towards or completion of the grant purpose. Grants are expensed for the current year that the grant commitment is made to the grantee.

### Functional Expenses
The costs of various Foundation activities have been accounted for on a functional basis in the consolidated statement of activities. Accordingly, certain costs have been allocated among the various activities.

Occupancy, depreciation and amortization, rental and maintenance of equipment and insurance expenditures are allocated based on the distribution of salary and benefit expenses. While such estimates are not conducive to precise determination, management believes the resulting allocations are reasonable.

### Management Estimates and Uncertainties
The preparation of consolidated financial statements in conformity with accounting principles generally accepted in the United States of America requires management to make estimates and assumptions that affect the reported amounts of assets and liabilities and disclosure of contingent assets and liabilities at the dates of the consolidated financial statements and the reported amounts of revenues and expenses during the reporting period. Accordingly, actual results could differ from those estimates.

### Income Taxes
The Internal Revenue Service has ruled that The Foundation qualifies under Section 501(c)(3) of the Internal Revenue Code (the “Code”) and is, therefore, not subject to tax on related income pursuant to Section 501(a) of the Code.

## 2. Pledges Receivable

The estimated fair value of pledges receivable, less a discount rate based on the date they are expected to be received, as of June 30 are as follows:

| | 2001 | | | 2000 |
|---|---|---|---|---|
| | Unrestricted | Temporarily Restricted | Total | Summarized Total |
| Unconditional pledges receivable: | | | | |
| Less than one year | $ 908,883 | $ 1,070,519 | $ 1,979,402 | $1,455,020 |
| One to five years | — | 870,695 | 870,695 | 854,253 |
| | 908,883 | 1,941,214 | 2,850,097 | 2,309,273 |
| Discount to present value | — | (52,644) | (52,644) | (92,820) |
| | $ 908,883 | $ 1,888,570 | $ 2,797,453 | $2,216,453 |

Conditional pledges have been made to The Foundation that have not been recorded in the accompanying consolidated financial statements. Conditional pledges as of June 30 have been made for the following purposes:

| | 2001 | 2000 |
|---|---|---|
| Research | $ 710,000 | $ 661,000 |
| General operations in future periods | 323,900 | 590,857 |
| | $ 1,033,900 | $ 1,251,857 |

Approximately 83% of the conditional pledges receivable at June 30, 2001 and 2000 are due from three contributors.

## 3. Fixed Assets

The fixed assets at June 30 are composed of the following:

| | 2001 | 2000 |
|---|---|---|
| Research facility | $ 1,084,476 | $ 1,084,476 |
| Furniture and equipment | 667,282 | 819,169 |
| Leasehold improvements | 27,116 | 54,563 |
| Total fixed assets | 1,778,874 | 1,958,208 |
| Less accumulated depreciation | (892,071) | (1,203,940) |
| Fixed assets, net | $ 886,803 | $ 754,268 |

## Notes to Consolidated Financial Statements

### 4. Permanently and Temporarily Restricted Net Assets

Temporarily restricted net assets at June 30 are available for the following purposes:

| | 2001 | 2000 |
|---|---|---|
| Research | $ 1,824,959 | $ 1,853,538 |
| Equipment purchases | 183,075 | — |
| General operations in future periods | 472,036 | 360,641 |
| | $ 2,480,070 | $ 2,214,179 |

Net assets are released from donor restrictions when expenses are incurred to satisfy the restricted purposes or by occurrence of other events as specified by donors. Purpose restrictions accomplished during the years ended June 30, were as follows:

| | 2001 | 2000 |
|---|---|---|
| Research | $ 5,018,984 | $ 5,171,190 |
| Public health education | 50,000 | — |
| Equipment purchases | 41,925 | — |
| General operations | 37,001 | 50,936 |
| | $ 5,147,910 | $ 5,222,126 |

The permanently restricted net asset balances are $500,000 and $495,940 as of June 30, 2001 and 2000, respectively. The investment income generated from the assets is restricted for research.

### 5. Research Programs

Research in retinitis pigmentosa, macular degeneration, Usher syndrome and related retinal degenerative diseases sponsored by The Foundation is conducted at various research facilities and generally covers periods of one to five years. Grants covering more than one year are subject to renewal based on recommendations of the Scientific Advisory Board ("SAB") of The Foundation and the ultimate approval of the Board of Trustees.

At June 30, 2001 and 2000, various programs and activities were underway and are reflected in the accompanying consolidated statements of financial position as follows:

#### Research Grants Payable

Research grants and awards payable represent amounts to be paid under existing grant awards total $6,259,681 and $5,081,529 as of June 30, 2001 and 2000, respectively.

#### Fixed Assets

Included in fixed assets is $542,374, which represents The Foundation's net investment in a research facility. The Foundation entered into agreements with a university involving monthly rental payments of approximately $2,700 relating to the use of The Foundation's research facility. The initial terms of the agreements, which are subject to the continuation of an existing operating grant or the obtaining of substitute grant monies, expire in September 2001, and there are renewal options for two additional five-year periods. All parties have indicated an intention to renew such agreements. Upon termination of the agreements the facility and all improvements become the property of the university.

## Notes to Consolidated Financial Statements

At June 30, 2001 and 2000, grants, which will be funded in future periods, contingent upon the recommendation of the SAB and the Board of Trustees' approval and, aggregated approximately $21,014,000 and $22,080,000.

### 6. Thrift Savings Plan

The Foundation maintains a thrift savings plan under the provision of Section 403(b) of the Code. The plan is available to all employees. For employees with one year of service or for employees who have been previously employed by a tax-exempt entity under Section 501(c)(3) of the Code, which had a benefit plan with Mutual of America, The Foundation will contribute 3% of the employee's base salary to the Plan. Additionally, for those employees meeting the above criteria, The Foundation will make matching contributions of 75% of an employee's contributions not to exceed 4% of the participant's compensation. Participants vest in the contributions made by The Foundation over a four-year period. The Foundation's contributions to the plan were $150,866 and $134,067 in 2001 and 2000, respectively.

### 7. Commitments

On June 1, 2001, The Foundation entered into a lease agreement for office space that expires on July 31, 2010. The lease requires monthly payments of $25,745 subject to annual escalation of approximately 3 percent over the period of the lease. These escalating future payments are presented in the schedule below to reflect straight-line recognition.

Future minimum lease payments related to The Foundation's noncancelable operating leases are as follows:

| | |
|---|---|
| 2002 | $ 373,198 |
| 2003 | 349,072 |
| 2004 | 343,467 |
| 2005 | 350,840 |
| 2006 | 337,446 |
| 2007 and thereafter | 1,461,289 |
| Total future minimum lease payments | $ 3,215,312 |

Occupancy rent expense totaled $280,391 and $201,462 for the years ended June 30, 2001 and 2000, respectively.

### 8. Related Party Transactions

Given The Foundation's singular focus on inherited retinal degenerative diseases, and the limited pool of relevant experts to serve as advisors and investigators, some overlap in The Foundation's operations and the research supporting the mission occurs. The Foundation's policy to mitigate this overlap requires that all grant applications be subject to independent evaluation by appropriate peer reviewers prior to grant commitment. The review and final approval process excludes anyone directly associated with the application and anyone, including SAB members, who in any other way has a recognizable conflict of interest. During fiscal year 2001 and 2000, The Foundation committed funds in the amounts of approximately $4,964,000 and $5,766,000, respectively, to research projects whose principal research investigators are also members of the SAB. Approximately $9,077,000 of the $21,014,000 contingent future grants in fiscal year 2001 and $12,844,000 of the $22,080,000 contingent future grants in fiscal year 2000 represent grants to fund research projects whose principal research investigators are also members of the SAB.

## OFFICERS

*Gordon Gund
Chairman

*Harriet L. Finkelstein
Vice Chairman

*Edward H. Gollob
President

*Peter K. Whinfrey
Senior Vice President

*Haynes P. Lea
Secretary

*William J. Chatlos
Treasurer

Bernard Berman
(1924-1996)
President Emeritus

Daniel Freedman
Vice President Emeritus

## NATIONAL TRUSTEES

*Stephen C. Barnett
*David Brint
*Joel P. Davis
*Steven Dezii
*Marilyn Green
*Howard Hirsch
*William F. James, Jr.
*John A. Johns
*Thomas A. Jones
*Alan R. Kahn
*Betti Lidsky
*Nathan R. Light
*Deborah Shaw
*Kenneth Wynn
Gregory A. Austin
Norman Barkeley
Michele A. Molloy-Barnett
Daniel G. Bergstein
Beverly Berman
Joseph Bier
Melissa Campbell, M.D.
Yvonne E. Chester
Robert D. Cleveland
Peter Coster
Joan E. Crowley
Sallie W. Cushner
Ralph L. Donnelly
Richard Elden
David Finkelstein
Gregory Furman
Thelma Godwin
Edward L. Goldberg
Dean Green
Bruce Grieve
Llura Gund
Louis Kearn
Alan B. Landis
Carlos Lidsky
Richard Lynch
Beatrice Cummings Mayer
M. Rose McCain
Patrick J. McGuinn
James P. McNiel
Sean Moynihan
Harry P. Oakes
Ann Rasch
Dana Robertson
Paul Saner
Bruce P. Sawyer
Ira Schulman
Otto J. Semrow
Stanley Shapiro
Jeremiah H. Shaw, Sr.
Moira Shea
Stephen B. Siegel
Mary Silverthorne
Meredith Tyree
George G. Villere
David G. Walsh
Elaine Welp
Theodore M. Welp
Stephen A. Wynn
R. Timothy Young

## TRUSTEES EMERITUS

Stanley Rosenberg
Alexander Yankelove

## SCIENTIFIC ADVISORY BOARD

Alan M. Laties, M.D.
Chairman

Raymond D. Lund,
Ph.D., FRS
Vice Chair

Gustavo Aguirre, V.M.D., Ph.D.
Robert E. Anderson, M.D., Ph.D.
Denis A. Baylor, M.D.
Jean Bennett, 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.
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.
Gordon E. Legge, Ph.D.
Maureen G. Maguire, Ph.D.
Roderick R. McInnes, M.D., Ph.D.
Ann Milam, Ph.D.
Jeremy Nathans, M.D., Ph.D.
Gary D. Novack, Ph.D.
Robert R. Rando, Ph.D.
Jose A. Sahel, M.D.
Johanna M. Seddon, M.D.
Edwin Stone, M.D., Ph.D.
Barbara A. Underwood, Ph.D.
Richard G. Weleber, M.D.
Donald Zack, M.D., Ph.D.
Marco Zarbin, M.D., Ph.D.

## EXECUTIVE STAFF

Robert M. Gray
Chief Executive Officer

Randall A. Hove
Chief Operating Officer

Gerald J. Chader, Ph.D., M.D., hc
Chief Scientific Officer

Harvey W. Cohen
Chief Development Officer

Ruth E. Shields, CPA
Chief Financial Officer

## FIELD OFFICES

Susan Abderholden
Executive Director
Illinois
(847) 680-0100

Terry Pink Alexander
Executive Director
Northern California
(510) 486-0461

Susan Brumley
Executive Director
Eastern Region
(919) 676-3300

Dennis Dickerson
Executive Director
Western Region
(801) 263-8554

Vivian Holmes
Executive Director
New York Metro
(212) 551-7807

John Householter
Executive Director
Texas/Oklahoma
(972)699-3336

Linda Stanard-Kovac
Executive Director
Washington D.C. Metro
(703) 267-2511

Penny Sugar
Executive Director
Florida
(954) 781-1551

The Foundation Fighting Blindness has affiliates and key volunteer groups in the following states: Alaska, Arizona, California, Colorado, Connecticut, Florida, Georgia, Illinois, Indiana, Kentucky, Maryland, Massachusetts, Michigan, Minnesota, Missouri, Montana, Nebraska, New Jersey, New York, North Carolina, Ohio, Pennsylvania, Rhode Island, Tennessee, Texas, Utah, Virginia, Wisconsin, and Wyoming. To contact any of our affiliate groups, call 1.800.683.5555, Extension 1174.

The Foundation funds research with money raised in a variety of ways. To find out more about how you can make your money work for you and The Foundation through planned giving, call 1.800.683.5555, Extension 1170.

The Foundation Fighting Blindess, 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. ❁



DESIGN: Manger, Steck and Koch
PHOTOS COURTESY OF: National Geographic, Jim Burger Photography, Cindy Elden, The Farinas, Control Delivery Systems
PRODUCED AND WRITTEN BY: Allie Laban-Baker and Tom Hoglund

THE FOUNDATION FIGHTING BLINDNESS, INC.

11435 Cronhill Drive
Owings Mills, Maryland 21117-2220

410.568.0150
800.683.5555
410.363.2393 FAX

www.blindness.org