



## **A CLEAR VISION FOR THE FUTURE 2006 ANNUAL REPORT**

The statistics are overwhelming. According to the World Health Organization (WHO):

- . 51 million individuals in the world today are diagnosed as blind.
- . 30 million individuals aged 65 years and over are blind.
- . 150 million have compromised or deteriorating eyesight.
  
- . 1.3 million individuals in this country are blind.
- . Nearly 800,000 individuals aged 65 and older are blind.

If something isn't done, 75 million people worldwide are expected to go blind by the year 2020; by 2030, an estimated 2.4 million Americans will be blind. Recognizing the importance of discovering new ways to combat blindness and eye disease and also to serve the needs of those with impaired vision and total vision loss, the Discovery Eye Foundation saw a clear vision of a threefold future:

### **DISCOVERY EYE FOUNDATION**

In celebration of its 35th anniversary and to better carry out the scope of its mission, in 2005, The Discovery Fund for Eye Research reorganized and renamed itself as the Discovery Eye Foundation. This name change reflects a renewed commitment to those served by the Foundation either through retinal and corneal research or through patient education and outreach programs.

With its name change, the Discovery Eye Foundation has further clarified its mission and vision statements.

#### **MISSION STATEMENT**

*Discovery Eye Foundation exists to facilitate the development of cures and improve patient care through retinal and corneal research and educational programs for eye disease.*

#### **VISION STATEMENT**

*Supporting worldwide educational programs and groundbreaking eye research wherever it is happening.*

## **FOUNDERS DEF HISTORY**

Founded in 1970 by Rita and Morris S. Pynoos of Beverly Hills, California, after their oldest son was diagnosed with keratoconus, the Discovery Eye Foundation began on a small scale to fund the research of a single ophthalmologist. Since that time, the fund has grown throughout the years to include two outstanding patient outreach programs and continues to fund cutting-edge eye research.

## **TODAY'S FOUNDATION RESEARCH**

Today, the Foundation's Medical Advisory Committee finds and supports researchers in their initial stages of groundbreaking eye research particularly as it relates to diabetic retinopathy, macular degeneration, ocular herpes, keratoconus and other degenerative conditions. These grants have supported many eye research projects producing unprecedented results, serving to attract some of the very best researchers in their fields. Most of the funded researchers are currently affiliated with the University of California, Irvine or Cedar-Sinai Medical Center, but Discovery Eye Foundation hopes to expand its support to other research institution in search of a cure for blindness.

Programs funded by DEF continued to expand in 2005 and impacted a wide variety of vision-related priorities. The organization continued its substantial support of scientists doing corneal and retinal work in the Morris S. Pynoos Eye Research Laboratory at the University of California, Irvine. DEF offers grants for promising studies that are in the early stages of investigation. This support has had a significant multiplier effect since many of the sponsored scientists have obtained substantial National Institute of Health (NIH) funding as a result of DEF support of their initial investigative findings. In fact, most of the **seven** NIH grants that were active in 2005 and yielded \$2.7 million in research funding were originally obtained with DEF underwriting.

These NIH grants and private foundation grants support research in areas such as age-related macular degeneration, diabetic retinopathy, keratoconus, ocular herpes, vaccines and genetics. Important progress was made in all these fields and new collaborations in mitochondrial diseases and stem cell research were broadened. By the end of the year, DEF-sponsored researchers had published 15 papers in basic science peer reviewed journals and six more papers were under review for publication in early 2006. When combined with clinical research performed at the UC Irvine Ophthalmology Department, the total papers published were 37, with seven more anticipated in 2006.

Overall, approximately sixty percent of DEF's budget is allocated to research to fund seed grants for groundbreaking projects.

**DISCOVERY EYE FOUNDATION  
THE SCIENTISTS**

Research scientists associated with the Discovery Eye Foundation are medical doctors and/or Ph.D.'s whose training and research qualify them as principal investigators and directors of their own research teams and projects. Some are practicing physicians who combine their careers in patient care with basic or clinical research. All have published scholarly papers in peer-reviewed professional medical journals.

**TRANSLATIONAL EYE RESEARCH  
PARAMETERS FOR RESEARCH SUPPORTED BY DEF**

*Translational research takes the best discoveries and innovations, and transforms them into diagnostic and therapeutic advances to help patients.*

- ❖ Research into the causes of and treatments for eye disease have always been an essential and defining part of the mission set forth by the Discovery Eye Foundation.
- ❖ Programs funded by DEF impact a wide variety of vision-related priorities. Substantial support of scientists doing retinal and corneal work in the Morris S. Pynoos Eye Research Laboratory at the University of California, Irvine, has led to significant breakthroughs in diagnosis and treatment of these eye disease.
- ❖ DEF offers grants for studies that are in the early stages of investigation enabling researchers to gather key information to apply for National Institutes of Health (NIH) and the National Eye Institute (NEI) grants in areas such as age-related macular degeneration, diabetic retinopathy, keratoconus, ocular herpes, vaccines, glaucoma and genetics.
- ❖ DEF collaborates principally with physician researchers affiliated with University of California, Irvine and Cedars-Sinai Medical Center to support clinical research. These physician scientists collaborate with ophthalmic companies to determine the safety and efficacy of drugs and lasers and to help develop new diagnostic and therapeutic approaches.
- ❖ The recent development and ongoing construction of the eye institute at the University of California, Irvine Medical Center has been a driving force in moving the Discovery Eye Foundation's research base operations from Cedars-Sinai Medical Center to Orange County. Scheduled to break ground in 2007, the proposed new eye institute will provide more space and improved, state-of-the-art laboratories and working conditions for DEF researchers as they work independently and collaborate with outstanding researchers in other university departments to find causes of and treatment for a wide variety of eye disease with a continued emphasis on corneal and retinal eye research.

**CORNEAL RESEARCH**  
**SUPPORTED BY THE DISCOVERY EYE FOUNDATION**

**KERATOCONUS**

- ❖ Ongoing research conducted by scientist at the Morris S. Pynoos Eye Research Laboratories at the University of California, Irvine, and the UCI Center for Molecular and Mitochondrial Medicine and Genetics, is leading to a better understanding of the ways to prevent programmed cell death or "apoptosis", which is the cause of many ocular diseases. The new field of mitochondrial research is aimed in great part at understanding how to prevent this cell death that is found in the aging and many diseases.

Oxidative stress can cause defects in mitochondrial DNA (mtDNA,) which is reported in Alzheimer's disease, prostate cancer, Parkinson's disease, diabetes and Down Syndrome. Ongoing research has shown that defects in mtDNA can cause certain forms of blindness, and that increased levels of damaged mtDNA are found in patients with keratoconus. This research may eventually explain the progression of keratoconus and open new avenues for prevention, diagnosis and treatments of many diseases, including keratoconus and age-related macular degeneration.

- ❖ In addition, researchers have found that oxidative stress could be aggravated in individuals with keratoconus through exposure to UV rays. It is recommended that patients with keratoconus protect their eyes from harmful UV rays and avoid rubbing their eyes or using poor-fitting contact lenses, which can increase trauma to the eye.
- ❖ DEF supported scientific studies have defined an important gene involved in the familial form of keratoconus. Researchers examined a major gene component that is known to be involved in the removal of reactive oxygen species. The gene defect they found in two families with keratoconus has not been observed in any previous study. Work is ongoing to determine the role that this gene defect might have in processing reactive oxygen species in keratoconus corneas— further evidence for the role of oxidative stress in keratoconus.
- ❖ Ongoing research into the ways corneal scarring occurs is helping to prevent scarring before it happens. Research funded by DEF is making progress with the help of a multiphoton laser confocal microscope, which allows researchers to create informative and detailed images to reveal hidden disease processes.

**OCULAR INFECTIONS**

- ❖ Research supported by DEF has made progress in understanding the molecular mechanisms of ocular herpes including its latency, reactivation, recurrence and scarring. Scientists continue to gain an understanding of LAT, the major virus gene active during herpes latency, including its central molecular role in keeping the virus latent between attacks and ways in which it inhibits the body's immune response to the herpes virus. Research shows that replacing LAT with an unrelated anti-programmed cell death gene results in a virus with normal reactivation, just like the normal virus. This strongly supports the hypothesis that LAT enhances reactivation and keeps the infection going in

the host by preventing programmed cell death in infected cells of the nervous system.

DEF supported scientists discovered two new herpes virus genes, AL and UOL that are involved in nervous system virulence, latency, and disease caused by herpes virus. This research is also supported by the NIH and NEI.

- ❖ Scientists supported by DEF (and NIH and NEI) are currently searching for a clinically feasible vaccine that would provide an effective and less costly means of preventing and treating ocular herpes. The underlying theme for these grants is to understand and eventually eradicate debilitating HSV infection of the eye and genital tract. Their findings are currently being evaluated in pre-clinical studies.
- ❖ DEF research supported by funding from the NIH is investigating how the herpes simplex virus escapes our natural immune system, which is another way the virus remains with us lifelong. Understanding this process could lead to therapies to eradicate this chronic infection.
- ❖ Patients stricken with herpes of the brain have a nearly zero chance of surviving. DEF affiliated scientists, with funding from the Neurology Institute, are investigating the causes of this fatal infection. They hope to soon work toward a vaccine for the more common forms of the disease, which cause genital and eye herpes, thereby eventually finding a vaccine for the most deadly form of the disease.

#### **CORNEAL TRANSPLANTATION, CORNEAL SCARRING AND ITS PREVENTION**

- ❖ Corneal transplantation is undergoing a revolution with new technologies that are being investigated to improve results, including lasers and the use of corneal stem cells.
- ❖ Scientists are studying the causes of corneal scarring after trauma, surgery and disease to understand the molecular causes and to harness new therapies to prevent corneal blindness.
- ❖ Regenerative Medicine and Biology is a new discipline being applied to the eye including the cornea as means to replace a cornea without corneal transplant surgery.

#### **RETINAL RESEARCH SUPPORTED BY THE DISCOVERY FOUNDATION**

#### **MACULAR DEGENERATION AND RETINITIS PIGMENTOSA**

- ❖ Research funded by DEF is currently ongoing to identify genes involved in Age-related Macular Degeneration (AMD), both deleterious and protective, and investigation of the ways specific genetic variations affect the clinical course and response to treatment of individuals.
- ❖ Ongoing research focused on examining and identifying yet to be discovered genes associated with AMD is critical.

- ❖ Scientists are involved in the examination of expressive level of genes in normal and diseased tissue to elucidate pathways affected by AMD, leading to new avenues of research and strategies for treatment of the disease.

#### **RETINAL REGENERATION CENTER AT UCI**

- ❖ DEF is a principal supporter the newly formed Retinal Regeneration Center whose future home will be at the proposed eye institute at UCI. The Center has already launched an impressive non-embryonic stem cell study that examines the treatment and prevention of human eye disease and the restoration of lost vision.

At this time, scientists have concluded that stem cells can significantly slow genetically caused degeneration of retinal cells in model systems of retinitis pigmentosa. Using non-embryonic stem cells, DEF supported researchers are working towards harnessing and modifying these stem cells to slow the progression of retinal degenerations, including AMD.

Research funded by DEF demonstrates that cells with similar properties can be isolated from the retina or brain and then transplanted back to treat diseases of these organs. Results in models have been promising, suggesting that such cells might be useful for treating human conditions such as retinitis pigmentosa, retinal detachment and macular degeneration and diseases that affect the optic nerve like glaucoma and trauma.

- ❖ DEF supported scientists are also working in the new field of “regenerative medicine” using non-embryonic stem cells to not only slow the progression of disease, but may be the key to restored vision in those who are already blind from retinal disease.

#### **OTHER RESEARCH SUPPORTED BY THE DISCOVERY EYE FOUNDATION**

##### **PEDIATRIC OPHTHALMOLOGY PROTOCOL HELPS PREMIES SAVE EYESIGHT**

Premature babies are surviving at younger ages than ever before only to battle with a blinding illness called retinopathy of prematurity (ROP). ROP is now the #1 cause of blindness in infants. Preliminary study data by Kenneth Wright, M.D. indicates that too much oxygen may be the main cause of ROP in premature infants. After a while, retinal tissue with no blood vessels sends out molecular signals demanding blood vessel growth. Instead of normal growth, however, fragile blood vessels sprout inappropriately, starting a cascade of events that can lead to retinal detachment and blindness.

Hospital intensive care units have gained the technical ability to sustain very low birth-weight babies, but it is this technology that accounts for the rise in ROP. Assisted fertilization procedures have also increased the number of multiple, low-weight births. Dr. Wright and the team at the Cedars-Sinai Neonatal Intensive Care Unit appear to have found a low-tech solution for a high-tech problem. Study results showed that severe ROP can be dramatically reduced by carefully controlling the oxygen dosage.

Since Dr. Wright helped start the low-oxygen protocol at Cedars-Sinai Medical Center, the County Hospital at USC, Good Samaritan Hospital and Singapore National Hospital have adopted it with very good results. Results from this concept were originally presented in a paper published in *Pediatrics* in 2003. This landmark publication was co-authored by Dr. Wright and supported by DEF.

#### **GLAUCOMA RESEARCH**

Glaucoma research is a very important strength at the UCI Department of Ophthalmology, both its medical and surgical treatment. The department's research interests are focused on the biomedical applications of lasers and in the development of new surgical approaches to the treatment of glaucoma. DEF supported scientists are helping to understand why surgical treatment for glaucoma sometimes fail and are in the process of designing treatments to improve surgical results.

#### **OPTIC NERVE REGENERATION**

The optic nerve and the retinal ganglion cells are the main targets of glaucoma and other diseases and damage to them causes permanent blindness. Non-embryonic stem cells in models of optic nerve damage show future promise of being able to regenerate retinal ganglion cells and the optic nerve.

#### **OPHTHALMIC CLINICAL RESEARCH**

The dedicated and continuous testing of drugs for viability, safety and effectiveness is essential. Moreover, throughout the extensive testing periods, doctors are able to provide wonderful advances in the treatment and great care for patients in need of immediate and innovative treatment.

The Discovery Eye Foundation is proud to be associated with these studies – such as those in the Ophthalmic Clinical Trials Center located at Cedar-Sinai Medical Center. These physicians affiliated with Cedars-Sinai Medical Center, such as James J. Salz, M.D. and Ezra Maguen, M.D. are on the cutting-edge of testing to find new treatments for eye disease. Currently, they are participating in three main studies.

- ❖ In a wavefront LASIK laser refractive surgery study, data and results were submitted to the FDA and are awaiting the FDA's approval for this important new surgical procedure. This technology will allow doctors to customize laser treatments to the specific diagnosis of the patient.
- ❖ Patients with an acute cornea eye infection participated in a drug study using new medication. Patients' eye infections were monitored and we are awaiting outcomes.
- ❖ The third study investigated the effectiveness of a new topical medication used on the eye during cataract removal.

The investigator physicians at the Ophthalmic Clinical Research Center created research protocols to study a number of other pertinent eye problems. These new protocols and more FDA clinical trials in refractive surgery are in progress and we eagerly look forward to their outcomes.

## **RETINAL RESEARCH AND THE RETINA VITREOUS ASSOCIATES MEDICAL GROUP**

Headed by David S. Boyer, M.D., who is a member of the DEF Board of Directors, the Retina Vitreous Associates Medical Group consists of six eye specialists who are board certified in ophthalmology and have completed formal subspecialty training in medical and surgical diseases of the retina, vitreous and macula. Each member of the group is nationally recognized for their participation in research and educational programs primarily aimed at understanding the causes of retinal diseases and developing novel treatments for retinal diseases.

In collaboration with M. Cristina Kenney, M.D., Ph.D., at UCI, the Group is helping to delineate the genetic risk factors that make some patients more sensitive or more resistant to macular degeneration.

The Group specializes in the diagnosis and treatment of retina, retina surgery, laser eye surgery, vitreous and macular diseases including macular degeneration, macular pucker, macular hole, diabetic retinopathy, retinal detachment, vitreous detachment, photodynamic therapy (PDT), central serous retinopathy, vitreous hemorrhage, transpupillary thermotherapy (TTT), anti-VEGF therapy (including Eyetech), uveitis, choroidal melanoma, vascular occlusion, CMV retinitis, and AIDS.

The Retina Vitreous Associates Medical Group works out of four offices including Cedars-Sinai Medical Center, is conducting roughly 30 clinical studies. A one-year trial with a drug called Lucentis is yielding promising results for patients with the “wet” type of macular degeneration.

## **DISCOVERY EYE FOUNDATION'S PATIENT EDUCATION AND OUTREACH**

DEF is home to the National Keratoconus Foundation and the Macular Degeneration Partnership, which provide the public with current and unbiased information on the two diseases. Through these outreach programs, DEF provides information to the public and eye care providers in accessible formats:

- Internet chat-rooms
- Free publications to patients and doctors
- Regular newsletters
- Free telephone access to healthcare professionals
- Support groups
- Two outstanding websites
- Patient educational seminars

With collaborative relationships with medical advisors, patients and the healthcare industry, each program serves as a clearing house for the most recent scientific developments and treatments. Both of these programs are affiliated or are members of the most prestigious ophthalmology associations and societies.



**MACULAR DEGENERATION PARTNERSHIP**  
**A DISCOVERY EYE FOUNDATION OUTREACH PROGRAM**

Since 1995, the Macular Degeneration Partnership (MDP) has provided patients and their family members facing the challenges of macular degeneration with education and support through newsletters, an award-winning web site, support groups and educational forums. The Partnership's Board of Medical Advisors includes many of the leading scientists and physicians involved in macular degeneration research and treatment.

Because of their support and collaboration, patients, families and their physicians can be sure of receiving the best quality information, unbiased by commercial goals or political concerns. At the same time, it provides complete information, including publishing unproven therapies or theories, so that patients and their families will have a safe location to read the pros and cons of each treatment.

**MDP VISION STATEMENT**

*We are patients, families, researchers, physicians, industry partners and workers in the fields of vision and aging. Our mission is to provide comprehensive, easily understood and up to the minute information about macular degeneration to the public through the Internet, telephone, public events and printed materials to support research and to coordinate advocacy efforts.*

**WHO MDP SERVES**

Age-related macular degeneration (AMD) is the leading cause of vision loss and legal blindness for people over the age of 60. It destroys the clear central vision needed for reading, driving, identifying faces and performing daily tasks. Over time, the individual is left only with a ring of peripheral vision.

In the United States an estimated 10 million people have significant vision impairment due to AMD. With the increasing age of the population, it is predicted that by 2010, 21 million individuals could develop AMD.

Despite the gargantuan proportions of this epidemic, most people are unaware of macular degeneration and have no knowledge of the things they can do to protect themselves from the disease. The most immediate and overwhelming need of older persons is access to accurate, timely and understandable information.

**MDP PATIENT EDUCATION AND OUTREACH**

In cooperation with the Discovery Eye Foundation, MDP has developed a variety of supportive and informational services free to all patients with macular degeneration, their families, and their doctors. Resources include:

- ❖ AMD Internet Website – The comprehensive, easy to navigate website provides immediate information about age-related macular degeneration to patients worldwide. The site is located at [www.AMD.org](http://www.AMD.org).
- ❖ MDP Support Groups – The AMD Support Group resource provides patients with a list of medical and service contacts in their area of the country. Group meetings that provide support for those with AMD are held regularly at Cedars Sinai Medical Center in Los Angeles.
- ❖ Patient Education Seminars and Resource Fairs – MDP sponsored seminars and fairs are open to the public. They provide informational materials and direct access to care providers and other important resources.
- ❖ MDP Newsletter – The large-print MDP newsletter is distributed biannually to those without access to the Internet. Topics include the latest in treatment developments, and patient profiles and experiences.
- ❖ Telephone Access – MDP provides a personal response, toll free "warm line", through which patients and caregivers can speak with a trained healthcare professional about managing AMD. The toll-free number is 888-430-9898.
- ❖ The MDP Signature AMD Toolkit – The popular toolkit includes a magnetic Amsler Grid (used to monitor patients' central field of vision), and important information and resources. It is designed to serve all patients with AMD, and is provided to doctors to distribute free of charge.

The root causes of macular degeneration are still unknown. MDP actively supports researchers in their work to find the causes of and a cure for the condition.

### **KERATOCONUS ( KEHR-a-toh-kohn-nus)**

Keratoconus (KC), is a non-inflammatory eye condition in which the normally round dome-shaped cornea progressively thins causing a cone-like bulge to develop. This results in significant visual impairment.

Keratoconus is a potentially blinding disease that affects thousands in the United States. National Keratoconus Foundation is the only known source for free publications on this debilitating condition that affects young and old. Patients can find information on corneal transplants, special contact lenses and Internet interaction with others impacted by the disease.

### **NATIONAL KERATOCONUS FOUNDATION A DISCOVERY EYE FOUNDATION OUTREACH PROGRAM**

The National Keratoconus Foundation (NKCF) was founded in 1986 to promote awareness of the condition and develop patient education and outreach to individuals and caregivers of those with keratoconus, a debilitating degeneration of the cornea that greatly distorts vision and affects people of all ages and backgrounds. Initially funded by a private grant from Jane and Norman Neely, NKCF was a direct response to Mr. Neely's frustration with the lack of useable information available when he was first diagnosed with keratoconus.

Today, NKCF, in partnership with the Discovery Eye Foundation, provides support and information about keratoconus to patients and their families. It is one of the nation's most comprehensive sources for patient information, including web-site access and a telephone line dedicated to answering patient questions. Most importantly, this is the only source for printed materials at no cost to the keratoconus community.

### **NKCF MISSION STATEMENT**

*To provide information and support to patients with keratoconus and their families; and to support research into the cause, treatment and eventual cure of keratoconus.*

### **WHO NKCF SERVES**

Keratoconus is a condition in which the normally round shape of the cornea thins and becomes distorted, causing a cone-like bulge to develop. This results in significant visual impairment and the distortion. Keratoconus patients are challenged by what used to be simple, every day tasks such as driving, operating a computer, watching television or reading.

Keratoconus is generally first diagnosed in young people - late teens and early twenties- a time when young adults are starting college and are choosing their careers. The impact of a progressive, vision threatening eye disease on such a young person is devastating. It is particularly difficult when traditionally there has been very little information available and often, very few people to speak with that truly understand this frustrating eye condition. It is estimated that keratoconus occurs in one out of every 2,000 persons in the general population. Most patients have not met another person with this condition and therefore, feel isolated and alone in dealing with the daily limitations imposed by both their diminished vision and their uncomfortable and costly contact lenses.

The majority of people with keratoconus are treated with specialized contact lenses due to the progressive changes of the keratoconus cornea. These lenses require frequent re-fittings and replacements. When the lenses no longer correct the vision adequately, approximately 20% of keratoconus cases will require corneal transplant surgery. Keratoconus patients have the single highest incidence rate for this surgery and there is no cure for this disease.

### **KC PATIENT EDUCATION AND OUTREACH**

NKCF is the nation's leading resource for patient information about keratoconus. It has developed a variety of programs to accomplish its mission and supports research and encourages researchers to work together to discover the causes, new technology for treatment and eventual cure of keratoconus. Services are offered for free to all keratoconus patients and their families.

- ❖ NKCF Newsletter - Published three times annually and distributed free of charge to over 14,000 patients and eye care professionals worldwide. The newsletter offers information on keratoconus, current research, new treatment options and insight into how others cope with this eye condition.
- ❖ Keratoconus-Link aka “KC-Link” - A free interactive e-mail based discussion group with over 2,000 members, KC-Link provides a vital resource for the KC community. Moderated by NKCF staff, the discussion group offers those with keratoconus a chance to communicate with others who understand the daily frustrations of living with this disease. A number of eye care practitioners - optometrists, ophthalmologists and contact lens specialists regularly participate.
- ❖ Patient Education - The NKCF publishes information about keratoconus and corneal transplant surgery at no cost to patients. Eye care providers also distribute these publications to their patients. In 2004, the “Corneal Transplant Surgery” booklet was introduced. (For more information, see below)
- ❖ NKCF Internet Web-Site – Located at <http://www.nkcf.org>, the site provides immediate information about keratoconus to patients worldwide.
- ❖ Patient Education and Support Program – The NKCF Toll Free Information Line, (800) 521-2524, is a resource through which patients, family members and healthcare professionals can speak with a registered nurse with a background in ophthalmology offering support, information and physician referrals.
- ❖ Transplant Buddy and OutReach Program – This support program pairs people with keratoconus with those who had corneal transplant surgery as a result of KC. Volunteers offer support to those newly diagnosed and those awaiting corneal transplant surgery that have concerns and questions that only someone who “has been there” can understand and answer.
- ❖ The NKCF Referral Program offers patients a list of KC specialists, grouped by state.
- ❖ Patient Education Seminar – Educational seminars bring keratoconus patients and their families together and offer the latest information on treatment and research from ophthalmology experts. For some patients, it’s the first time meeting with others who suffer from this condition. Plans to expand the program were instituted for seminars in other cities.
- ❖ Tissue procurement program - NKCF collects and disburses corneal tissue to scientists for research into the causes and progression of this disease.
- ❖ NKCF also funds scientific grants to promote research of keratoconus
- ❖ Currently, NKCF offers the following free publications to those who have keratoconus.

“What is Keratoconus? A Reference Guide for Patients and Their Families,” is a 24 page booklet explains keratoconus in easy to understand language. The fifth edition

is the only patient information material of its kind. Available in English and Spanish, it is sent to patients and eye care providers worldwide. We send out nearly 10,000 copies a year.

“Corneal Transplant Surgery: A Reference Guide for Patients and Their Families” provides information for the more than 40,000 people in the United States who undergo corneal transplant surgery each year. This booklet provides a definition and overview of the surgery. It includes discussions on why one might consider this kind of surgery, when it is appropriate, what to ask your doctor and lists possible risks and complications.

NKCF Newsletter is published three times a year. It keeps our database of approximately 14,000 people abreast of the latest developments in treatments, research, new products, and contact lenses that aid those with keratoconus. The Newsletters often profile people who are dealing with the condition so that other may benefit from their experiences.

Due to the large Hispanic population in the United States, NKCF offers all materials in Spanish. Keratoconus information is also available in Hebrew, Polish, French and Portuguese.

No other health organization provides patients and doctors with literature about keratoconus, making NKCF’s educational materials truly on-of-a-kind . Because we are not affiliated with products or funded by other associations/organization the information provided is objective and based on the best medical advice available from our team of medical advisors. These materials serve thousands of people, having a positive impact on keratoconus patients and their families worldwide.

### **DISCOVERY EYE FOUNDATION TODAY’S CHALLENGES**

The number of individuals who are blind or suffer from vision loss in the United States alone is staggering. And, as reported by WHO, that number continues to grow exponentially each year. The difficulties suffered by those with vision loss are huge.

Moreover, as the baby-boomer population ages, more and more individuals will suffer from cataracts and vision degeneration. This is a problem that affects us all – not only in terms of personal eye health, but as tax-payers.

According to the National Federation of the Blind:

- ~ 74% of the working-age blind are unemployed.
- ~ The estimated annual cost of blindness to the U.S. federal government is \$4 billion.
- ~ The cost of lifetime support for one blind person is nearly \$1 million.

Unfortunately, government programs for both research and patient education are overburdened. The already faltering Medicare/Medicaid system is unprepared for the cost of vision loss and unable to provide adequate information and education to those suffering from vision loss.

### **TOMORROW'S OPPORTUNITIES**

The future is clear. To combat the rising darkness that threatens to engulf us, organizations like the Discovery Eye Foundation must continue its important research and work.

According to Dr. C. Everett Koop, former Surgeon General of the United States, every research dollar invested by the federal government between 1900 and 1975, has seen a \$13 return. That's a 1,300 percent return on investment.

Dr. Koop went on to express his regret that of the estimated \$600 million spent annually in the United States each year on healthcare, less than 3 percent was earmarked for use by research scientists. Like many others, Dr. Koop urged a modification of our spending priorities, noting that while we spend an estimated \$3,000 per year per American for healthcare, we spend only \$35 per person for biomedical research.

Eye care research is conspicuously under-funded in the United States. It is for these reasons that the community as a whole must partner together to address this growing issue. By supporting the Discovery Eye Foundation, corporations, foundations and individuals will noticeably impact our ability to continue eye care research and patient education programs. In addition, supporters play a vital role in the financial and societal health and well-being of our community and our world – allowing us to envision a brighter future for all.

The Discovery Eye Foundation depends on financial support from individuals, corporations, and private foundations as well as grants from the National Institutes of Health. Your support allows DEF to continue our work as we provide outreach and educational materials to those with eye disease, empowering individuals with vision loss to learn more about their conditions and to find ways to overcome their limitations and thrive.

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