

Winter 2009



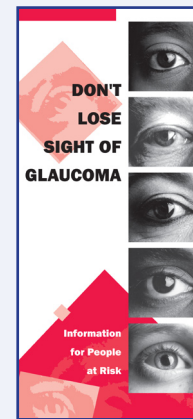
Letter from the Chair of the NEHEP Planning Committee

Public health has been described by the Institute of Medicine as “fulfilling society’s interest in assuring conditions in which people can be healthy.” The National Eye Health Education Program (NEHEP), a long-running public health effort by the National Eye Institute (NEI), supports initiatives to enhance vision care throughout the United States. NEHEP seeks to develop strategic efforts to educate the public and to promote eye exams so that vision health is integrated into people’s lives. As I begin my term as Chair of the NEHEP Planning Committee, I am honored to follow in the footsteps of towering figures in the community of vision care providers—Dr. Bradley Straatsma, Dr. Alfred Sommer, and most recently Dr. Eve Higginbotham—and I look forward to working with leaders in the fields of ophthalmology and optometry to advance our shared mission.

Broadening the reach of high-quality vision care requires increasing awareness among healthcare professionals and the public of scientifically-based health information that can be applied to preserving sight and preventing blindness. NEHEP currently has four educational programs focusing on areas of unmet need: awareness of glaucoma and its treatment, vision health concerns and dilated eye examinations related to diabetes, the needs of people with low vision, and building bridges to connect Hispanics to vision health services. Plans are being developed to add a program focusing on older individuals including attention to age-related macular degeneration (AMD).

The current direction of NEHEP reflects a conscious decision to organize educational programs around populations that are at risk rather than around a specific eye condition. A motivation for re-orienting educational programs around at-risk populations rather

Educational Resource Spotlight: *Don’t Lose Sight of Glaucoma* brochure



Order this and other materials online at <http://catalog.nei.nih.gov/>.



Healthy Vision Community Programs Database

This easy-to-search resource can help you learn about new ways to address eye health issues and replicate eye health-related projects in your community. Visit the Healthy Vision Community Programs Database at <http://community-based.shs.net/>

than around health conditions is that communities do not tend to organize around health complaints; as with all NEHEP programs, we will continue to monitor the success of the strategy.

The power of information is a theme that unifies many NEHEP programs. According to findings from the joint NEI and Lions Clubs International Foundation survey of knowledge, attitudes, and practices among adults living in the U.S., 90 percent of adults report having heard of glaucoma, but only 8 percent of this group is aware that there are no early warning symptoms for glaucoma.

Similarly, NEI-sponsored population-based studies have found that more than half of individuals who meet criteria for a glaucoma diagnosis are unaware that they have the disease. Research also shows that certain subgroups: African Americans over age 40, people over age 60, especially Mexican Americans, and those with a family history of the disease are at elevated risk and need to be informed about both their disease risk and the importance of comprehensive dilated eye examinations to check for glaucoma. January is Glaucoma Awareness Month and offers a great opportunity to do this. The NEHEP Glaucoma Education Program offers a variety of targeted resources and suggestions for educational efforts, and you can find these materials at <http://www.nei.nih.gov/nehep/programs/glaucoma/index.asp>.

The National Eye Health Education Program is coordinated by the National Eye Institute, National Institutes of Health, U.S. Department of Health and Human Services. This administrative document may be reprinted without permission.

My colleagues and I on the NEHEP Planning Committee are eager to strengthen the coalition of concerned individuals and organizations working to make vision care a public health priority. We salute your involvement in efforts to prevent blindness and to treat chronic eye diseases, and we look forward to working together.

Anne Louise Coleman, M.D., Ph.D.

Chair, National Eye Health Education Program Planning Committee
Frances and Ray Stark Professor of Ophthalmology
Jules Stein Eye Institute
David Geffen School of Medicine at UCLA
and
Professor of Epidemiology
UCLA School of Public Health

KAP Highlight: Glaucoma

It is estimated that 2.2 million adults in the United States aged 40 and older have been diagnosed with glaucoma and this number will only increase, reaching an estimated 3.3 million by 2020, because of the rapidly aging U.S. population.¹

Glaucoma has no warning signs or symptoms, and if left untreated, can cause permanent vision loss. Treatments to slow the progression of the disease are available. However, at least half of those who have glaucoma are not receiving treatment because they are unaware of their condition.



Normal Vision



Vision with Glaucoma

The Knowledge, Attitudes, and Practices Related to Eye Health and Disease (KAP) Survey is a national survey conducted in English and Spanish by the National Eye Institute (NEI) and the Lions Clubs International Foundation. KAP provides information about eye health and disease among adults who self-report being told by

an eye care provider (ECP) (i.e., an ophthalmologist or optometrist) that they have glaucoma or are suspect for glaucoma. Please note that the use of “all adults” in the information that follows refers to all KAP survey respondents.

Regarding their general health, 67 percent of adults with glaucoma and suspect for glaucoma describe their health as good, very good, or excellent, compared with 83 percent of all adults who describe their health the same way.

Sixty-eight percent (68%) of adults with glaucoma and suspect for glaucoma, and 43 percent of all adults report having been told by a healthcare provider (HCP) that they have one or more chronic health conditions including: high blood pressure, arthritis, diabetes, heart disease, and cancer.

Among the 97 percent of adults who report having heard of glaucoma and suspect for glaucoma, 20 percent know that there are no early warning symptoms for glaucoma. Only 8 percent of all adults know that there are no early warning symptoms for glaucoma.*

When asked about eye care practices, more than 90 percent of all adults as well as adults with glaucoma and suspect for glaucoma, respectively, report having had their eyes examined by an HCP, which could have included a primary care provider (PCP) or ECP. Among the 95 percent of adults with glaucoma and suspect for glaucoma who report having had their eyes examined by an HCP, 93 percent report having had their pupils dilated during an eye examination. The same holds true for 76 percent of all adults.

Results from the KAP Survey found that recommendations from PCPs, family members, and coworkers had the greatest influence among adults with glaucoma and suspect for glaucoma to have an eye exam.

Given that only 8 percent of all KAP Survey respondents know that there are usually no early warning signs for glaucoma, highlights the need to educate all adults about the importance of regular comprehensive dilated eye examinations that will facilitate its timely discovery. The National Eye Health Education Program (NEHEP) is using the survey information to continue to develop and implement targeted efforts to raise awareness about glaucoma. Other organizations can use these findings in developing their own eye health education outreach.

* Reported knowledge about glaucoma and suspect for glaucoma is based on respondents' answers of *True*, *False*, or *Not Sure* to specific statements.

For more information about the KAP Survey and to download a full copy of the report, visit <http://www.nei.nih.gov/kap/>.

Reference

¹The Eye Diseases Prevalence Research Group. (2004). Prevalence of open-angle glaucoma among adults in the United States. *Archives of Ophthalmology*, 122(4), 532–38.

January is Glaucoma Awareness Month...

...a great time to raise awareness in your community about this disease that has no warning signs.

Although treatments to slow the progression of the disease are available, at least half of those who have glaucoma are not receiving treatment because they are unaware of their condition.¹ Fortunately, a comprehensive dilated eye exam can detect glaucoma, and early detection may minimize vision loss. People at higher risk for glaucoma include African Americans over age 40, people over age 60, especially Mexican Americans, and those with a family history of the disease.

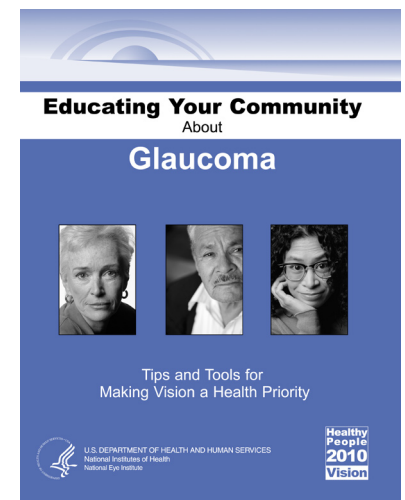
The National Eye Institute (NEI) offers a wide variety of resources that you can use to help educate the public about glaucoma and the importance of having a dilated eye exam to detect it. You will find them at <http://www.nei.nih.gov/glaucomaeducation>.

For ideas about how to get the word out, be sure to look at *Educating Your Community About Glaucoma*. This resource, part of the Healthy Vision Toolkit, contains facts about glaucoma, activity suggestions, promotional materials, and a brochure.

Visit the National Eye Health Education Program Glaucoma Webpage at <http://nei-dev.shs.net/nehep/programs/glaucoma/index.asp> for additional suggestions about community activity outreach opportunities.

Reference

¹National Eye Institute & Lions Clubs International Foundation. (2007). *2005 survey of public knowledge, attitudes, and practices related to eye health and disease*. Bethesda, MD: National Eye Institute. Available at: <http://www.nei.nih.gov/kap/>.



Glaucoma Research Foundation: Innovation in Education and Support



When Darlene Ruffell learned that Dr. Robert Shaffer was the founder of the Glaucoma Research Foundation (GRF), she wrote an e-mail to the foundation's information specialist, in which she said: "Thank you so much for all the information you have sent me on glaucoma. I have been trying to cope with this disease for many years. My mother has glaucoma and my grandmother went blind from it. My mother remembers traveling from Pasadena to San Francisco to see Dr. Shaffer back in the late 1960s. He never even sent her a bill—what a nice doctor! I find it really ironic that here I am now finding information from a foundation he started 30 years ago. Again, thank you so much for giving me all this info to read

about my disease, to help me understand and cope with it."

Every day, the GRF helps people like Darlene cope with the difficulties of having a sight-stealing disease. For those coping with glaucoma, as well as their caregivers, the GRF provides resources and materials designed to address a variety of concerns. And because of the generous support from donors across the country, all these materials are made available at no cost.

The GRF publishes a free newsletter, *Gleams*, that goes out three times a year to more than 75,000 homes nationally—*Gleams* contains helpful articles covering research breakthroughs, eye care tips, resources for those living with glaucoma, and highlights of Foundation activities.

Patient education publications are provided free from GRF, and from the offices of many eye doctors and prominent glaucoma specialists. GRF's comprehensive 32-page booklets *Understanding and Living With Glaucoma* (in both English and Spanish), and *Childhood Glaucoma: Facts, Answers, Tips and Resources for Children with Glaucoma and their Families* dispense valuable information about this potentially blinding eye disease. Additionally, recently updated educational brochures provide critical information for those at highest risk: African Americans and Hispanics in older age groups. All publications are available free from the Glaucoma Research Foundation Website, www.glaucoma.org, or by calling toll-free 1-800-826-6693.

The GRF strongly supports NEHEP's mission to make vision a health priority, and encourages all those at risk for glaucoma to actively participate in preserving and protecting their vision. The Glaucoma Research Foundation mission: prevent vision loss from glaucoma by investing in innovative research, education, and support with the ultimate goal of finding a cure.

For more information contact Andrew Jackson at ajackson@glaucoma.org.

NEHEP Welcomes New Partnership Organizations

The National Eye Health Education Program (NEHEP) is pleased to welcome two new organizations to the NEHEP Partnership—the National Rural Health Association (NRHA) and the National Association of Chronic Disease Directors (NACDD).



The mission of NRHA is to improve the health of rural Americans and to provide leadership on rural health issues through advocacy, communications, education, and research. NRHA activities bring together residents of rural communities, rural health professionals of all specialties, representatives of state, local, and national governments, and the full range of private sector rural health organizations. NRHA programs serve rural communities by providing relevant and timely information and best practices to all people who care about the health of rural America.

The NACDD provides state-based leadership and expertise for chronic disease prevention and control at the state and national level. The National Vision & Eye Health Work Group of the NACDD works with state leaders for the development of state-based vision programs, enhanced vision surveillance, and comprehensive and coordinated strategies in promoting eye health and vision preservation that can serve as the basis for collaborative initiatives at the state and national levels.



The purpose of the NEHEP Partnership is to establish ongoing, interactive, mutually beneficial relationships with the National Eye Institute and other organizations to achieve NEHEP goals and objectives.

To learn more about the NEHEP Partnership visit <http://www.nei.nih.gov/nehep/about/partnership.asp>.

Vision Care Access and Quality of Life in Nursing Homes

Access to eye care for seniors in nursing homes is a nationwide problem. Bailey noted that visual impairment is a leading cause of disability in the United States.¹ Currently, there are 18,000 nursing homes nationwide with 1.9 million beds and 84 percent occupancy. The provision of eye care services at these facilities varies from state to state. Most facilities do not have a plan for eye care services for their residents. Nursing homes have minimal responsibility for the provision of eye care to residents suffering from glaucoma and diabetes, and patients with hypertension, stroke, and other systemic ailments have no guidelines assuring patient protection from asymptomatic, high-risk catastrophic vision loss.



It is evident that visual function, eye health, and the co-morbidities associated with aging are crucial areas of healthcare concern. Concurrently, increased prevalence of visual impairment with increasing age further emphasizes the importance that residents' receive comprehensive and periodic eye care. A comprehensive vision assessment serves many significant purposes:

1. Provides data on the functional status of the eyes and neurosensory system.
2. Takes into account the special visual needs of residents.
3. Provides crucial data about ocular health and the potential for systemic problems causing catastrophic vision loss.
4. Allows for the formulation of a treatment, management, counseling, and education plan for the residents' future care.

Blindness and visual impairment can be managed with early detection and treatment; however, it is well known that most patients suffering from eye disease lack symptoms until sight is irreparably lost. Unfortunately, few residents receive comprehensive vision exams after being admitted into a skilled-care facility, in spite of ominous statistics. Vision impairment in nursing facilities is 13–15 times more common among institutionalized elderly people than non-institutionalized elderly people. Therefore, early ocular intervention strategies are crucial and must be supported by facility administrators and families. Family members responsible for medical decision making, physicians, and other healthcare professionals are not familiar with strategies of establishing eye exam guidelines. It is incumbent upon eye care professionals to partner with healthcare providers to set eye exam guidelines, and encourage family members to provide active support for the resident to overcome these barriers to personalized health care. It has been estimated that 80 percent or more of all nursing home residents received no eye care after admission into the nursing facility. The creation of a proactive and cooperative professional team approach to senior eye care will optimize quality of life.

For more information contact William A. Monaco, O.D., MEd., Ph.D. at flightsight@earthlink.net.

Reference

¹ Bailey, R.N., et al., *Optometry*, Vol. 77, No. 6, June 2006 "Visual Impairment and Access to Eye Care in Adult Texans, 50 years of age and over."

AFB/NAPVI FamilyConnect Brings Together Parents of Visually Impaired Children

When parents learn their child has a visual impairment, it can be overwhelming. Parents not only worry about the physiological effects of blindness and how it will affect their child's well being, but they also deal with a variety of emotions that come with the diagnosis and have questions about their child's future. They wonder, "Will my child fall behind at school?" or "What can I expect at the eye doctor's office?" or "Where

can I find services that will help my child?” The answers to these and other questions can be found at the newly launched FamilyConnect™—an online, multimedia community located at www.familyconnect.org.

With only 93,600 visually impaired school-aged children in the U.S., over half of whom have additional disabilities, it’s easy for families facing vision loss to feel alone. To help these families connect with each other and give busy parents, grandparents, and other caretakers a place to find comprehensive resources and support 24 hours a day, the American Foundation for the Blind (AFB) and the National Association for Parents of Children with Visual Impairments (NAPVI) launched FamilyConnect in the spring of 2008.



AFB’s comprehensive research and information, along with NAPVI’s broad-reaching base of families, have combined to create this unique resource. Visitors to the site have the opportunity to create a personal profile and receive information on news and events geared toward their child’s age, eye condition, and zip code. Parents have access to a glossary of eye conditions, message boards, tips on what to ask a child’s eye care specialist, videos of families, a parent-authored blog, links to local resources, and featured sections dedicated to multiple disabilities, technology, education, and every age group from infants to teens.

“When I talk to parents of visually impaired children, they almost always ask about three things: they want to talk to other parents who have children with the same eye condition as their child, they want access to the latest health and education information, and they want to know what the future holds,” said Susan LaVenture, Executive Director of NAPVI. “FamilyConnect offers parents all these things—and more—in one place.”

The goal of www.familyconnect.org is to provide connections and support. By providing accurate information and creating a forum for meaningful discussion, families and their visually impaired children will feel empowered to reach their full potential.

For more information contact Caitlin McFeely at cmcfeely@afb.net.

Educating Communities About Eye Health Through Lions Eye Health Program

Education is a key means to combating eye disease worldwide. Through annual eye care visits, educational materials, and community support, the prevalence of vision loss can greatly decrease. A study conducted by Lions Clubs International Foundation (LCIF) and the National Eye Institute (NEI) further demonstrates the lack of awareness about eye health. It shows that most adults in the United States value their eyesight, however, they lack knowledge of how and when to seek timely detection and treatment of eye diseases.



The Lions Eye Health Program (LEHP) is confronting this lack of education about eye health in communities, where people are often unaware of the appropriate steps to ensure proper eye health. Even in high-income countries, a significant number of people remain crippled from vision loss.

Seventy-one percent (71%) of respondents from the NEI study reported that a loss of their eyesight would rate as a 10 on a scale of 1 to 10, meaning that it would have the greatest impact on their day-to-day life. However, only 8 percent knew that there are no early warning signs of glaucoma, a group of diseases that can damage the eye's optic nerve and result in vision loss and blindness. These startling statistics demonstrate that there is a lack of sufficient eye health education in communities.

LEHP is a community-based eye health education program that aims to prevent vision loss by promoting early detection and timely treatment of eye diseases like glaucoma and diabetic eye disease. Because the program encourages people to visit an eye care professional, it is most appropriate for communities with an established eye care system already in place. For this reason, LEHP has been the primary SightFirst activity for Lions from high- and middle-income countries. LEHP has been active in the United States, Japan, the British Isles and Ireland, Canada, Australia, and Turkey. With support from Campaign SightFirst II, Lions can continue to promote eye health and disease prevention throughout all countries.

“Lions have long been champions of people who are blind and visually impaired. By better educating the public on the need for regular eye exams and timely treatment of eye diseases, we can end preventable blindness,” said Mahendra Amarasuriya, Chairperson, LCIF.

Through screenings, community events, and educational materials, awareness of proper eye health is increasing in communities where LEHP is present. Together, LCIF and Lions are helping the public become more educated about preventable blindness.

For more information contact Alecia Dimar at Alecia.Dimar@lionsclubs.org.

NEI Launches New Web Design

The National Eye Institute (NEI) is pleased to announce a redesign of its website, www.nei.nih.gov. The new design incorporates findings from a consumer satisfaction survey, usability testing, and current web usage research. New features on the website include:

- A dynamic “Highlights” section to showcase vision research findings, scientific meetings and conferences, clinical trials, publications, and programs.
- An update service that visitors can subscribe to and receive e-mail messages about new web content.



The screenshot displays the National Eye Institute website's new design. The header features the NEI logo, the text "National Eye Institute National Institutes of Health Research Today...Vision Tomorrow", and a search bar. The main content area is organized into several columns and sections:

- Navigation:** A vertical list of links including About NEI, Health Information, News and Events, Research Funding, Research at NEI, Education Programs, Jobs, and Resources.
- Eye Health Information:** A featured topic section for "Uveal Coloboma" with a descriptive text and a "Find out more" link.
- News and Events:** A section with a "Subscribe" button and a list of recent news items, such as "Neuroscience and the National Eye Institute: Vision Research Presentations at Neuroscience 2008".
- Research Funding:** A section with a brief description of grant and contract support.
- Research at NEI:** A section describing basic and clinical research conducted by NEI staff.
- Professional Resources:** A section listing various databases and networks like eyeGENE, Strategic Planning in Vision Research, and VISION Network.
- Education Programs:** A section highlighting the National Eye Health Education Program (NEHEP) and other resources for children.
- Highlights:** A section with a "See All You Can See, NEI's Website for Kids" link and a small image of a child.

- A featured eye health topic.
- A text tool that allows visitors to change the font size with a single click.

NEI launched its first official website in 1997 and received less than 100,000 unique visitors that year. Today the website boasts nearly 2.5 million unique visitors annually.

Comments, questions, and requests for updates can be sent to Kym Collins-Lee, NEI Website Manager, kcl@nei.nih.gov.

HHS Releases New Healthfinder.gov



The U.S. Department of Health and Human Services has released a more user-friendly version of healthfinder.gov. The site offers quick and easy information and tools to help people stay healthy and prevent disease.

Coordinated by the Office of Disease Prevention and Health Promotion (ODPHP) and its National Health Information Center, the redesign of healthfinder.gov was informed by health literacy and usability principles and tested with more than 650 users. The result is a consumer health website that's easy to understand and navigate, especially for people who have limited health literacy.

Be sure to visit healthfinder.gov's *Quick Guide to Healthy Living*, a new resource that uses everyday language and examples to:

- Tell users how to take action to improve their health using a “small-steps” approach.
- Give users positive reasons to change their behavior.
- Provide tools and encouragement, such as personal health calculators, menu planners and recipes, tips for caregivers, and printable lists of questions to take to the doctor.

You also may try out the new “myhealthfinder” tool, which provides personalized health recommendations based on sex, age, and pregnancy status. This feature offers evidence-based recommendations from the U.S. Preventive Services Task Force, an independent panel of experts in prevention and primary care sponsored by the Agency for Healthcare Research and Quality.

Visit the new healthfinder.gov today and help spread the word about this exciting new resource. For instructions on how to link to healthfinder.gov, please visit <http://www.healthfinder.gov/aboutus/linking.aspx>.

Healthy Vision Community Award Spotlight: West Virginia Health Right, Inc.

West Virginia Health Right, Inc., is a free clinic that serves over 18,000 uninsured, impoverished citizens in a 32-county area of south-central West Virginia. As a 2008 Healthy Vision Community Award (HVCA) recipient, the WV Health Right Glaucoma project is designed to provide health education and promote good eye care to reduce visual impairment due to glaucoma. Low-income adults aged 16–64, who have no health insurance and receive their medical, dental, and pharmacy services at the clinic are the focus for these efforts. A variety of approaches are used to implement the project. According to Patricia H. White, Executive Director of WV Health Right, “The glaucoma project has educated a high-risk population about a disease that they would not be aware of until their vision was affected. We know from our screening program we have saved the vision of 11 patients so far. That’s a huge success!”



To improve the clinic’s quality of care, staff members receive training about glaucoma and the importance of eye exams. This enables them to provide information when they engage in one-on-one interactions with patients during medical visits to the clinic.

Educational materials describing glaucoma, identifying risk factors associated with the condition, and promoting regular eye examinations are distributed to patients. These materials are obtained from the National Eye Institute, and several other sources including the Centers for Disease Control and Prevention, American Academy of Ophthalmology, American Optometric Association, Prevent Blindness America, and leading medical colleges and hospitals. If necessary, clinic staff members develop materials to ensure that readability is appropriate for the patient population. Medical staff members, including family nurse practitioners, registered nurses, and certified medical assistants are responsible for reviewing materials with each patient and documenting the discussion in the patient’s chart/Electronic Health Record.

To increase awareness about glaucoma and the importance of good eye care, information displays are exhibited in the clinic’s waiting areas on two large bulletin boards, as well as in eight exam rooms, and two health education rooms. The displays are typically done in January—National Glaucoma Awareness Month, and May—Healthy Vision Month, as well as other times during the year.

A retired ophthalmologist volunteers one day a week in the clinic’s eye operatory for glaucoma testing and treatment at no cost to WV Health Right patients. In addition, the clinic developed a resource list of community providers that perform free glaucoma testing for low-income adults.

Discussion and materials about glaucoma are also incorporated into education outreach activities that WV Health Right staff provide to businesses, senior citizens and women’s groups, and other organizations.

Since January 1, 2008, some of the accomplishments of the Health Right Glaucoma project include:

- Screening 247 patients for glaucoma.
- Diagnosing glaucoma and providing treatment for 11 patients by the clinic's volunteer ophthalmologist.
- Training 15 staff members about glaucoma and eye screenings.
- Reaching an estimated 1,200 people through numerous educational outreach activities.

For more information about the WV Health Right Glaucoma project, contact Patricia White, at 304-414-5911 or healthrigh@aol.com.

To learn more about the HVCA Program, visit www.healthyvision2010.org/news/hvca.