

Summer 2009



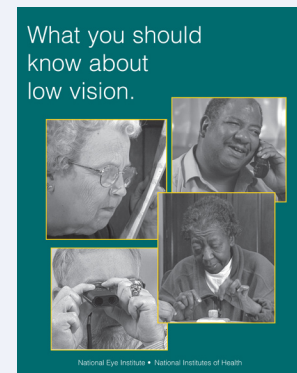
Letter From the Chair of the NEHEP Planning Committee

This year marks the 40th anniversary of the National Eye Institute (NEI), the first government organization solely dedicated to research on human visual diseases and disorders. NEI supports vision research through grants and training awards made to scientists at more than 250 medical centers, hospitals, universities, and other institutions across the country and around the world. In addition, NEI conducts laboratory and patient-oriented research at its own facilities located on the NIH campus in Bethesda, Maryland. To mark this milestone, NEI has been planning a series of special events. You can read more about these activities in the article *NEI Celebrates 40 Years on the Frontier of Vision Research*.

Science and technology continue to fuel improvements in eye care. While there have been numerous innovations in recent years in the diagnosis and treatment of eye disease, the public's ability to benefit from these gains has been limited. Many people do not receive timely eye care, allowing eye diseases to develop into advanced stages and delaying potentially sight-saving treatment. Others never learn about services or devices that might have enhanced their ability to engage in activities of daily living that have become difficult or impossible due to vision loss. As with other facets of health care, a multitude of environmental, behavioral, and social factors serve as barriers to accessing appropriate eye care.

Two of the articles in this issue of *Outlook* focus on the challenge of access to care. *Variables That Influence Access to Eye Care* discusses findings from NEI-supported interviews with officials from five government agencies and five nongovernmental organizations about factors that influence the receipt of health care and eye care, specifically considering care that may prevent vision loss. *FocusFirst: An Alabama Student Vision Initiative*, featured in the Healthy Vision

Educational Resource Spotlight:
*What You Should Know
About Low Vision* brochure



Order this and other NEI
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/>.

Community Awards Spotlight, discusses efforts being made to address the vision care problems of children living in poverty in Alabama, where a variety of barriers exist in both rural and urban areas to the provision of proper eye care.

As science continues to move forward in discovering new ways to sustain eye health and to prevent vision loss, we must continue to address the challenge of making quality care widely available and accessible. We would like to hear from you. Please let us know about your efforts to reach out to those who face difficulty in accessing vision care, as we are interested in expanding the scope of efforts by eye care professionals that have proven themselves through successful application in the field.

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

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.

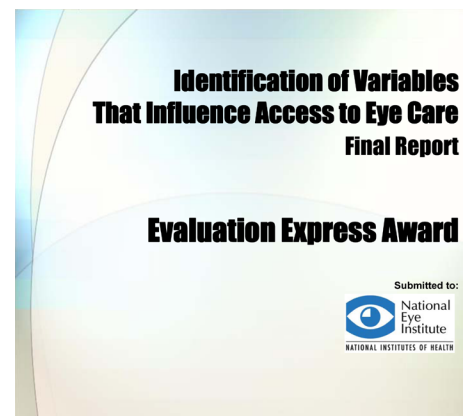
Variables That Influence Access to Eye Care

In 2004, the National Eye Institute (NEI) interviewed representatives from 10 government agencies and nongovernment organizations to gather information about factors that influence the receipt of health care, in particular care that may prevent vision loss. The federal government agencies represented were:

- Agency for Healthcare Research and Quality
- Centers for Medicare and Medicaid Services
- Indian Health Service
- Office of Minority Health
- Health Resources and Services Administration

The nongovernment organizations that participated were:

- American Academy of Ophthalmology
- American Optometric Association
- Kaiser Family Foundation
- RAND Health
- Robert Wood Johnson Foundation



The purpose of this research was to identify barriers to care and to determine best practices and strategies used by other agencies and organizations to deal with those barriers. The National Eye Health Education Program (NEHEP) uses this information to better design educational materials and programs and collaborate with other government agencies and nongovernment organizations that specifically address access-to-care issues.

The discussion protocol for the interview included the following topics:

- Eye and/or health programs or services provided to the general population.
- Key factors that influence the receipt of eye and/or healthcare services.
- Variables that were more likely to influence receipt of eye and/or healthcare services for high-risk populations.
- Opportunities for individuals and agencies to collaborate and address access to eye and/or health services.
- Strategies and/or approaches the vision community can consider to effectively deal with barriers to the receipt of eye care.

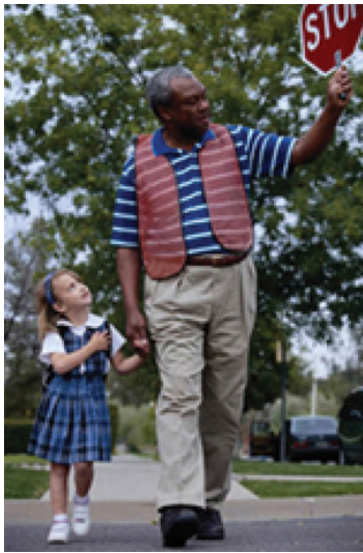
In general, barriers to the receipt of eye and/or healthcare services that were mentioned ranged from insurance status and type of insurance, availability of providers, and language barriers, to transportation, health literacy, and patient perceptions. There was a consensus that barriers to the receipt of general health care may be the same barriers to the receipt of eye care.

The majority of all agency and nongovernment organizations mentioned insurance status as a key factor in the receipt of healthcare services. The issue of patient perceptions regarding the need for care was also mentioned in a majority of interviews. Ultimately, health literacy dictates patient perceptions. To be an efficient consumer of health care, one must be knowledgeable of disease processes and the prospects of preventive care to avoid unnecessary morbidity and mortality. Health literacy was mentioned as a barrier in more than half of the interviews conducted.

The information captured in the interviews resulted in the *Identification of Variables That Influence Access to Eye Care Final Report*. In addition to providing a complete list of variables and a discussion of key factors that influence the receipt of eye and/or healthcare services, the report addresses strategies, methods, or approaches that those interviewed felt were most effective in dealing with barriers to care. You can access the full report at http://www.nei.nih.gov/nehep/research/FinalReport9_15_05.pdf.

Applications Now Available for 2010 Healthy Vision Community Awards

The National Eye Institute (NEI) recognizes the importance of strengthening the capacity of community-based organizations (CBOs) to expand existing eye health education programs and start new ones. The Healthy Vision Community Awards (HVCA) Program of NEI provides up to \$10,000 in seed money to



nonprofit CBOs to support grassroots eye health education efforts. NEI encourages you to help make vision a health priority in your community by applying for a 2010 award or encouraging others to apply.

Nonprofit organizations including, but not limited to, CBOs and groups, minority-based organizations, schools, faith-based organizations, civic and fraternal groups, and local health departments and agencies may apply. Universities and university-affiliations, such as medical centers, are precluded from receiving an award directly, but are welcome to collaborate with CBOs.

Proposed projects must support the vision objectives in Healthy Vision 2010, which aim to improve the eye health of the Nation through prevention, early detection, treatment, and vision rehabilitation. Projects must focus on eye health education and promotion, be innovative, and have the potential for

sustainability once funding ends.

Applications for the 2010 funding cycle are now available. Program information and application forms are available at www.healthyvision2010.org/news/hvca. Please make note of these important dates:

- August 31, 2009—Postmark due date for receipt of application
- March 2010—Award recipients are notified

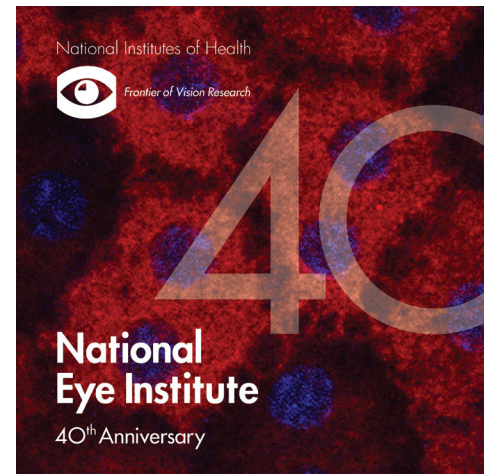
If you have questions about the application package or eligibility requirements, please e-mail your questions or requests to HVCAMail@shs.net.

To find program ideas or to search for programs that have been funded in your state, visit the Healthy Vision Community Programs Database at <http://community-based.shs.net/>.

NEI Celebrates 40 Years on the Frontier of Vision Research

In 2009, we mark the 40th anniversary of the National Eye Institute (NEI) with a year-long celebration that includes a film screening, scientific symposia, and other commemorative events.

NEI was established on August 16, 1968, when President Lyndon B. Johnson signed Public Law 90-489. The new National Institutes of Health (NIH) institute was the first government organization solely dedicated to research on human visual diseases and disorders. NEI officially began operations on December 26, 1968, and the National Advisory Eye Council met for the first time on April 3, 1969.



For the anniversary celebration kickoff, NEI recently hosted a screening of “Blindsight,” a documentary of a blind man’s mountain climbing journey with six blind Tibetan teenagers. Speakers at the event included Erik Weihenmayer, the film’s star; Mike Oberdorfer of NEI’s extramural program; and Robert Beckman, president and CEO of Wicab, Inc., which developed a vision device known as BrainPort with NEI support.

As part of the anniversary, NEI is sponsoring a symposia series, with each symposium emphasizing interdisciplinary research efforts. The first symposium, “Genetics and Genomics in Vision,” took place on April 17 and offered an opportunity for geneticists, biologists, clinicians, and clinician-scientists to examine the impact of genetics research on vision research. The next symposium, on June 1 and 2, “Advances in Optical Imaging and Biomedical Science Symposium,” examined the relationship between technology and clinical diagnosis in ophthalmology. Four upcoming symposia will highlight topics including neuroscience, glaucoma, and novel therapeutic paradigms and blindness.

These and other 40th anniversary events will showcase past, present, and future projects intended to keep NEI at the forefront of vision research for many years to come.

To learn more about NEI, visit www.nei.nih.gov.

NEHEP Welcomes New Partnership Organization



The National Eye Health Education Program (NEHEP) is pleased to welcome a new organization—VisionServe Alliance—to the NEHEP Partnership.

The mission of VisionServe Alliance is to engage leaders in building a better world through services to people with vision loss. The purpose is to build and nurture a healthy and vibrant network of nonprofit organizations throughout the United States and Canada whose

services enrich the lives of those living with severe vision loss and to remove the barriers to the pursuit of opportunities. To learn more about VisionServe Alliance and what they do, visit www.agenciesfortheblind.org.

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>.

Educational Series Targets Disease, Trains Personnel

Retina-related diseases continue to be one of the fastest growing sources of vision loss among adults over age 60 in the United States. As a large number of “boomers” enter this high-risk demographic, the eye care field is compelled to address this developing issue. To combat the problem, the Joint

Commission on Allied Health Personnel in Ophthalmology® (JCAHPO®) has developed the educational series *Retina TechTrax*™. This new educational forum focuses on innovations in retina specialty and educates eye care personnel through advanced training, instruction, and discussion.



Leading specialists guide eye care professionals through lectures and discussions on new retina technologies and unique solutions. Attendees can also earn continuing education credit toward JCAHPO certification while discovering the latest advancements in this subspecialty. The 4-hour program includes audience participation in discussions and breakout sessions that focus on the evaluation of current and future treatments of diabetic retinopathy and age-related macular degeneration.

JCAHPO leadership was responsive to the growing incidence of retina disorders in certain patient demographics and keen to take action. The organization began development of the program in collaboration with Focus-ED, and was supported by an unrestricted educational grant from Genentech, Inc.

“Retina-related degeneration is a chief concern in eye care as a growing elderly demographic face the challenges of retina degeneration and disease,” notes JCAHPO President William F. Astle, M.D., FRCS(C), Dipl. ABO. “We developed *Retina TechTrax*™ as a platform for eye care professionals to discuss the challenges that this field confronts and learn about effective educational and treatment solutions for the future.”

Retina TechTrax™ will be featured at 10 select JCAHPO continuing education programs throughout North America, with two additional programs planned for 2010. The course will also be featured at the 2009 JCAHPO Annual Continuing Education (ACE) program in San Francisco, CA, October 23–27, as part of an entire day devoted to subspecialty education and training.

“This is a great opportunity for eye care professionals to engage subject matter in a productive and instructive setting with some of the nation’s leading retina specialists,” adds Astle.

Retina *TechTrax*SM is part of JCAHPO's ongoing educational and training initiatives available to eye care professionals. In addition to continuing education programs and events, JCAHPO also offers training, education, and credit-earning opportunities and resources online and through the organization's bookstore.

For more information about the Retina *TechTrax*SM series or JCAHPO, visit www.jcahpo.org or call 1-800-284-3937.

EyeCare America Reminds Older Americans to "Keep Your Independence"



Imagine not being able to read the newspaper, watch television, or drive your car. These are a few of the things many older people have trouble doing, due to vision loss from various eye diseases. In fact, by the age of 65, one in three Americans has some form of vision impairing eye disease. During tough economic times, those on fixed incomes are often the most affected, and as daily and monthly expenses are prioritized, eye care often falls by the wayside.

In light of this, EyeCare America is reminding older Americans to "Keep Your Independence" by getting a simple, painless eye exam. This national health campaign is intended to remind older Americans about the value of eyesight and encourage people 65 and older to call EyeCare America's Seniors EyeCare program to determine if they qualify to be matched with a volunteer ophthalmologist for a no-cost eye exam and up to one year of care.

"Thank you all so very much for giving me my eyesight back so that I can do the things I love most, seeing my husband, children, grandchildren and my great grandchildren," said Melva Rayles, an EyeCare America patient from Warner, Oklahoma.

The program provides a comprehensive eye exam and care for any disease detected in the initial visit for up to one year, at no out-of-pocket cost to the patient. To see if you, a loved one or a friend, 65 and older, is eligible to receive a referral for an eye exam and care, call 1-800-222-EYES (3937), available 24 hours a day, every day.

The Seniors EyeCare Program is designed for people who:

- Are U.S. citizens or legal residents;
- Are aged 65 and older;
- Have not seen an ophthalmologist in 3 or more years;
- Do not belong to an HMO or the VA.

In addition to its Independence campaign, EyeCare America has teamed up with celebrity chefs from across the country to provide eye healthy summertime recipes that include foods rich in vitamins and antioxidants. Visit www.eyecareamerica.org to learn more about EyeCare America and to download the organization's *Feast Your Eyes on This!* summer cookbook. This season, make it a point to celebrate your independence as you enjoy both the sights and tastes of summer!

New Resources for Eye Care Professionals From AFB

When a person is diagnosed with vision loss, patients and their doctors frequently do not know where to turn because they may not be aware of the services that are available to help them cope with vision loss and gain the skills they need to continue living full, active lives. To help eye care professionals provide the help and hope patients need, the American Foundation for the Blind (AFB) Senior Site® (www.afb.org/seniorsite) created the Resources for Eye Care Professionals (www.afb.org/seniorsite/fordoctors) section.



Experts at AFB collaborated with a national advisory group of ophthalmologists for recommendations on resources that eye care professionals need to help their patients through the vision loss diagnosis.

This section provides simple tools that doctors can use to help patients and family members find the resources, help and support, specialized products and technology, and links to services and information that can help them in their everyday lives.

Features of the section include:

- Easily downloadable brochures and fact sheets that can be shared with patients, family members, and staff members.
- Videos available in English and Spanish, including a vision simulation video that shows what a person with vision loss is experiencing.
- Links to the other sections of Senior Site, AFB's award-winning website for people experiencing age-related vision loss, and their family members.

In addition, talking to patients about losing vision is something that all doctors dread. Doctors are trained to give the good news about how to save vision or restore sight, but they can't do that for everyone. As the number of older persons with vision loss continues to grow, it's inevitable that more doctors will need to be prepared to deal with patients' emotions about vision loss, and provide comfort and support. The **Talking to Patients about Visual Impairment** section provides tips on setting the stage when explaining the diagnosis, talking to the patient about next steps, and helping them find resources.

With proper resources and support, older Americans with vision loss can lead fulfilling and independent lives. It's imperative that eye care professionals are aware of these resources, sensitive to patients' needs, and supportive during the diagnosis and thereafter. Together with AFB's Senior Site, doctors can make this transition period easier and more successful.

For more information, contact Adrianna Montague-Gray at amontaguegray@afb.net or 212-502-7675.

Charter Helps Patients Navigate Through Macular Disease Diagnosis



Quietly closing the office door, 70-year-old Carol Taylor* walked in silence with her daughter by her side. Carol didn't notice that it was a beautiful, warm day with a gentle breeze and a dramatic blue sky that almost matched her eyes.

Carol was in shock. She just learned from her doctor that she had age-related macular degeneration (AMD), an incurable disease that would slowly steal her vision. Carol anticipated the worst—a full, independent life cut short by a disease whose name she did not know until 30 minutes ago.

Carol is one of millions of people affected by AMD. This devastating disease not only has the potential to cause vision loss, but it can lead to severe depression and a reduced quality of life. But Carol's story doesn't have to end here. All too often patients are overwhelmed by their diagnosis and unaware that there is hope, and help, in the way of lifestyle modifications and nutritional supplements to slow the disease, medical treatment if the disease becomes severe, aftercare supports, and low vision rehabilitation.

That is why AMD Alliance International (AMD AI) developed the Macular Disease Patient Charter. The Charter, developed *for* patients and *by* patients, helps people living with the disease navigate the way to proper care, treatment, and a better quality of life.

There are four essential cornerstones in the Charter:

- 1) Prevention and cure;
- 2) Timely diagnosis;
- 3) Universal access to proven treatment;
- 4) Holistic care and support.

“This charter is extremely important as it sets out a path in which patients, doctors, communities, service organizations, and governments can work together in a positive way,” said Wanda Hamilton, chief executive officer of AMD AI. “We know that if at the time of diagnosis patients like Carol get critical referrals to low vision rehabilitation, counseling and aftercare, their quality of life is vastly improved.”

The Charter was unanimously endorsed by all 60 of the members of AMD AI. With members in 25 countries, it is the only international organization in the world dedicated exclusively to promoting awareness, treatment, and research into macular disease.

Plans are underway by AMD AI to further promote and distribute the Charter. Recently AMD AI members presented the Charter to the Pope in Rome and a news feature about the Charter was published in the April 2009 issue of *Retina Today*.

For more information, or to discuss how your organization can help distribute the Charter to patients, contact Allie Laban-Baker at allie.labanbaker@amdalliance.org.

Download a copy of the Charter at www.amdalliance.org.

*Not her (Carol's) real name.

New “Children’s Sports Eye Safety” Brochure Available

While participating in sports can have a healthy influence on kids, it also carries an increased risk of eye injury. A new brochure from Prevent Blindness America—made possible by a grant from the Transitions® Healthy Sight for Life Fund—helps those in a position to make a difference understand the danger, and teaches them how to protect children’s eyes and become advocates in their communities. Targeted toward caregivers, school personnel, and athletic coaches, the guide includes:



- A description of the various types of risk factors that exist (depending upon the type of sport and level of physical contact).
- General recommendations for eye protection for many popular sports.
- A section on UV protection during sports participation and beyond.
- A checklist to aid consumers in recognizing eye injuries and assessing the level of emergency assistance required.
- Tips for becoming an advocate for the use of protective eyewear anywhere and anytime sports are played.

“Now that approximately half of all kids are involved in at least one organized athletic activity, the need for protective eyewear has never been more urgent,” said Hugh R. Parry, president and CEO, Prevent Blindness America. “With almost *all* sports eye injuries being preventable, it is both tragic and unnecessary that a lack of awareness on this topic continues to exist. We hope that by educating adults, we are creating advocates for eye safety—on an individual and a community-wide level.”

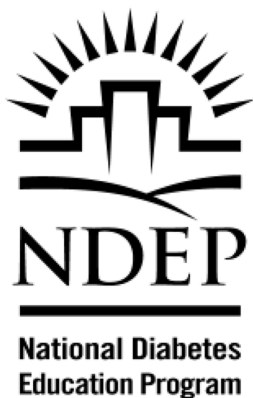
The brochure is available to consumers through Prevent Blindness America and to eye care professionals via the Transitions Optical, Inc. point-of-sale ordering system. It was also distributed during the Transitions Championship for Healthy Sight official PGA TOUR event at Innisbrook Resort and Golf Club, on March 16, when the focus of the Transitions “Live Your Vision” pavilion was “Sports Vision Protection.”

“When we find new ways to educate consumers, it provides opportunities for eye care professionals to engage in more productive discussions about the importance of protective eyewear,” according to Mary O’Hara, regional giving officer and professional communications specialist, Transitions. “Education—especially early in life—is the surest way to enact long-term change in healthy eye habits.”

The “Children’s Sports Eye Safety” brochure is available at Prevent Blindness America (www.PreventBlindness.org) and the Transitions Healthy Sight for Life Fund (www.HealthySightforLife.org). Eye care professionals can request complimentary copies of the brochure to use in-office or at community events by visiting www.Transitions.com/POS or calling Transitions Optical Customer Service at 1–800–848–1506.

The National Eye Institute also has sports eye safety information and educational materials available at www.nei.nih.gov/sports.

NDEP Offers Community Outreach Kit To Reach Older Adults With Diabetes



In recent years, the number of people with diabetes in the United States has more than doubled. Almost 24 million people—about 8 percent of the population—currently have diabetes. Americans of all ages, races, and ethnicities are vulnerable—especially older adults. In fact, more than 12 million adults age 60 and older have diabetes. Awareness, education, early diagnosis, and proper treatment are critical to preventing or delaying serious complications, including diabetic retinopathy.

The National Diabetes Education Program (NDEP), a joint program of the National Institutes of Health and the Centers for Disease Control and Prevention, recently developed *The Power to Control Diabetes Is in Your Hands Online Community Outreach Kit* for organizations that conduct health education programs for older adults. This outreach effort focuses on the importance of promoting a comprehensive approach to controlling diabetes by managing blood glucose (blood sugar), blood pressure, and cholesterol; taking prescribed medications; making healthy food choices; and engaging in regular physical activity to help older adults live longer, healthier lives. Kit contents include:

- A calendar of sample promotional activities;
- Tools to implement promotional activities; and
- Campaign resources, including brochures in English and Spanish, fact sheets, feature articles, presentations, and radio and print public service advertisements.

Senior centers, churches, libraries, and other community organizations play an important role in reaching older adults with important health information. NDEP encourages groups to promote diabetes messages using the *Power to Control Diabetes* tools. The kit can be found at: http://www.ndep.nih.gov/media/campaigns/Power/Power_index.htm.

Healthy Vision Community Awards Spotlight: Impact Alabama: FocusFirst

Impact Alabama was incorporated in June 2004 as the state's first nonprofit organization dedicated to developing and implementing substantive service-learning projects in coordination with students from more than 20 universities and colleges throughout Alabama. FocusFirst is an Impact Alabama initiative that provides a cost-effective, direct response to the vision care needs of tens of thousands of children who live in urban and rural poverty in Alabama. These needs are largely the result of poor public awareness about the importance of eye care in young children and the inability of children to recognize their own vision problems. Financial hardship and lack of access to appropriate medical care heighten these problems in families from economically disadvantaged backgrounds.

The innovation of FocusFirst lies in its reliance on a curriculum-based service-learning model that utilizes a workforce of undergraduate and graduate students who receive academic credit for their service. The Impact Alabama staff members who supervise them are recent college graduates who commit to a year of stipend-based volunteer service—similar in cost and structure to the AmeriCorps VISTA program.



Under the supervision of Impact staff members, the students ensure that children who are 6 months to 5 years of age and enrolled in Head Start and lower-income daycare programs are screened for vision problems using technologically advanced photo-optic scan cameras. The students attend a training session during which they receive instruction on how to operate the vision screening equipment, conduct a vision screening appropriately, and work with the children being screened. Staff members supervise the students as they conduct vision screenings. Students use a high-tech photorefractive camera that takes a photograph of the child's eyes. The photo is then analyzed by professionals at Vision Research Corporation. All children who fail the screenings receive subsidized follow-up care through Sight Savers of Alabama, a nonprofit Impact Alabama partner.

In addition, the FocusFirst Administrator discusses the importance of early vision screenings with all daycare directors with whom she speaks and provides educational materials to go home to parents of the children who are screened. Each Head Start program or daycare director is provided with a fact sheet on the importance of early detection of eye problems and the problems that can result if vision problems are not found and treated appropriately.

More than 1,700 college and university students throughout Alabama have participated with FocusFirst. Over the last 4 years, these students have screened more than 54,000 children in all 67 counties across the state, with approximately 12.1 percent of the children failing the screenings and receiving subsidized follow-up care as necessary through Sight Savers of Alabama.

As a 2009 Healthy Vision Community Awards recipient, the Impact Alabama FocusFirst program initially projected a 50 percent increase in the number of centers reached the previous year, from 425 to 640, increasing the number of children screened in all 67 counties from 13,507 to more than 16,000 children. By the end of the 2009 academic year, FocusFirst exceeded the original goals by screening more than 22,000 children at more than 700 Head Start and daycare centers. Ongoing efforts also include providing information and educational materials to both daycare workers and parents that address the importance of early vision screenings and eye care.

For more information, contact Stephen Black by phone at 205-348-6494 or by email at sblack@impactalabama.org.
