OUR T.A.K.E. ON GLAUCOMA

A Declaration from the Glaucoma Working Group to Take Action to Know Your Eyes

Foreword

Today, more than 40 million Americans are 65 or older. By 2050, it is estimated that figure will rise to 88.5 million. Our nation is aging rapidly, and this demographic shift likely means longer hospital stays, more doctor visits, and greater healthcare expenditures for more and more Americans. If you’re a Baby Boomer looking ahead to your silver years, you already have plenty to think about: retirement, the economy, elderly parents, and young adult children. It’s hard to find time to focus on your health — especially if you feel healthy!

One condition that’s often overlooked as we age is glaucoma — damage to the optic nerve that can lead to progressive, irreversible vision loss. Glaucoma is one of the leading causes of blindness in the world, affecting 60.5 million people today and set to reach 79.6 million by 2020. Early detection and proper management can help prevent the serious outcomes of glaucoma. Yet for some reason, the disease continues to be under-diagnosed and associated with poor treatment adherence.

Why is glaucoma often overlooked by patients, when eyesight is so precious? We convened a panel of experts known as the Glaucoma Working Group to address this question. The group examined the underlying challenges surrounding glaucoma diagnosis and management, and proposed solutions to help educate, motivate, and empower two audiences: those who are at risk for glaucoma but are not diagnosed (“undiagnosed patients”) and those who have been diagnosed but may be under-treated (“diagnosed patients”).

This document contains an overview of the Glaucoma Working Group’s discussions, which may be of interest to eye care professionals (ECPs), advocacy groups, and policymakers. It also includes a powerful call to action that we hope will inspire you — the patient — to take an active role in managing glaucoma and help protect the gift of sight.
In closing, we would like to thank the Glaucoma Working Group for their involvement and contributions.

Scott R. Christensen
President & CEO
The Glaucoma Foundation

Daniel P. Perry
President & CEO
Alliance for Aging Research

TAKE on Glaucoma is an educational program developed, in partnership, by The Glaucoma Foundation, the Alliance for Aging Research, and Merck, and is funded by Merck.
Issues and Insights from the Glaucoma Working Group

Through a series of robust discussions, the Glaucoma Working Group identified numerous challenges—as well as underlying perceptions and behaviors—that stand in the way of optimal diagnosis and care. One clear insight emerged: patients must be their own best advocate for eye health. With ECPs (eye care professionals) facing time constraints and logistical challenges, it’s up to the patient to be an active partner in care—voicing concerns, following through on visits, and following treatment plans. The Glaucoma Working Group agreed that while future innovations may one day lessen the burden of care, there is no substitute for an educated and empowered patient.

Challenges in Glaucoma Diagnosis

Glaucoma is a group of eye diseases which in most cases is associated with increased pressure within the eye (also known as elevated intraocular pressure or IOP). There are many different types of glaucoma. Primary open-angle glaucoma is the most common form of glaucoma. In the U.S., more than 2 million individuals are estimated to be living with glaucoma, and that number is expected to increase by 50%, to more than 3 million, by 2020. However, glaucoma continues to be under-diagnosed.

The Glaucoma Working Group agreed that a major factor in the under-diagnosis of glaucoma is that many older Americans do not consider glaucoma a personal health issue, even though their age alone puts them at risk. Here are some of the underlying reasons the Glaucoma Working Group identified for this lack of concern:

- **Risk factors:** Many Americans may be unaware of the risk factors for glaucoma, and therefore might not recognize that they could be at risk
- **Symptoms:** Glaucoma is a “silent” disease, meaning it may progress without symptoms until irreversible damage is done. A lack of symptoms could be perceived as a lack of disease
- **Competing health concerns:** Older Americans face a growing risk for numerous diseases, many of which are perceived as more serious than glaucoma
- **Identification:** While Americans overall may know that age plays a role in glaucoma risk, “younger” aging Americans may be reluctant to think of themselves as old enough to worry about an age-related disease
Insight: Americans ages 40 and older must be better educated about the risk factors for glaucoma, the silent nature of the disease, and its potentially serious outcomes.

The American Optometric Association recommends that healthy adults receive a comprehensive eye exam every two years until age 60 and once a year thereafter (more frequently if risk factors are present). A comprehensive exam includes a dilated examination of the optic nerve, which is needed to help diagnose glaucoma. However, the Glaucoma Working Group concluded that many Americans do not visit their ECP often enough, and may not always receive a dilated exam when they do. In 2002, for example, only 55 percent of U.S. adults had received a dilated eye exam in the past two years. The Glaucoma Working Group identified the following reasons patients may not receive a comprehensive, dilated eye exam:

- **Lack of awareness:** Patients may not recognize the importance of dilation in diagnosing glaucoma, and will not request dilation if it is not offered to them.
- **Inconvenience:** Patients may be resistant to dilation because they do not want their vision to be blurred afterwards. ECPs also may consider dilation an inconvenience, and therefore not offer it.
- **Confusion:** Patients may mistakenly believe that a “puff test” — which an ECP uses to measure eye pressure by delivering a quick puff of air onto the eye — is enough to detect glaucoma. To accurately diagnose glaucoma, patients must receive a dilated eye exam.

Insight: Americans must be educated about the components of a comprehensive eye exam, the importance of dilation, and the difference between a dilated exam and a puff test. Patients must be empowered to voice questions and concerns during ECP visits.

**Challenges in Glaucoma Care**

The best way to manage your glaucoma is by detecting the disease early and working with your ECP to create a disease management plan that works for you. Your eye doctor may recommend prescription eye drops, laser treatment, or another type of surgery.

Poor adherence to a disease management plan and to follow-up care is pervasive among patients diagnosed with glaucoma. In one study, at least two-thirds of patients with primary open-angle glaucoma and ocular hypertension discontinued their therapy within the first year. Another study showed that patients with poor adherence were five times more likely to experience disease progression compared with patients with good adherence. The Glaucoma Working Group identified some of the potential reasons for poor adherence, including:
• **Personal conflicts:** For many patients, scheduling issues and personal priorities can overshadow glaucoma care. Patients may find it difficult to stick with their treatment plan when they are traveling, working a lot, or caring for other family members.

• **Cost and access challenges:** Patients may prioritize other health care expenses over follow-up visits to the ECP and prescribed treatments.

• **Symptoms:** Because glaucoma often has no symptoms, patients may not see a tangible benefit to adhering to prescribed treatment plans, which may include taking medication daily, and may not feel motivated to do so.

• **Demographic factors:** Different races and ethnicities have different beliefs and behaviors when it comes to taking medication, many of which can play a role in adherence.

• **Administration:** Some patients, especially those who are elderly, may have difficulty with administering their medication, which can lead to unintended missed doses.

**Insight:** Adherence issues are complex and often are not addressed directly by the ECP. Patients must be educated about the potential outcomes of poor adherence and be motivated to proactively address their individual adherence challenges.

**A Call to Action to Educate and Empower Patients**

*The Glaucoma Working Group suggests the following actions for undiagnosed patients:*

1. **F.R.A.M.E. Your Risks**
   Take control of your eye health by understanding the risk factors for glaucoma and discussing them with your ECP. Remember the acronym “F.R.A.M.E.”:

   • **Family History:** Studies have consistently shown that people with a family history of glaucoma are at an increased risk for the disease. In fact, if you have a family member with glaucoma, you may be seven times more likely to have glaucoma yourself.

   • **Race:** Several studies have shown that African-Americans and Hispanics are at an increased risk for glaucoma. In fact, glaucoma is about four to five times as prevalent among blacks as whites.

   • **Age:** Age is a strong risk factor for developing glaucoma. The risk increases considerably at age 40 for African-Americans and at age 60 for the general population.

   • **Myopia:** Studies suggest that if you have myopia (nearsightedness), you have about double the risk of developing glaucoma compared with people without myopia.

   • **Eye Pressure:** High eye pressure (also called intraocular pressure, or IOP) is the most important risk factor for the development of glaucoma. However, not all patients who have glaucoma have high eye pressure.
Additional risk factors for glaucoma include low central cornea thickness, diabetes, hypertension, eye trauma, and use of steroids.\textsuperscript{23,24}

2. Observe the Nerve
It’s important to visit your ECP for regular, comprehensive eye exams (every 1 to 2 years depending on age and risk factors) to evaluate and maintain your eye health.\textsuperscript{24} A comprehensive eye exam can also show signs of non-ophthalmic diseases such as hypertension and diabetes.\textsuperscript{24}

A comprehensive eye exam includes a dilated examination of the optic nerve.\textsuperscript{13} This exam is very important because damage to the optic nerve can be a sign of glaucoma.\textsuperscript{3} Another important part of the exam is an eye pressure test (sometimes called a “puff test” or tonometry).\textsuperscript{13} High eye pressure is a major risk factor for the development of glaucoma, so it’s a good idea to have your eye pressure tested regularly.\textsuperscript{16} However, it’s important to understand that not all patients who develop glaucoma have high eye pressure.\textsuperscript{22} This is why the puff test alone is not enough — you must have a dilated exam to fully explore the health of your optic nerve.\textsuperscript{13}

\begin{center}
\textbf{In a healthy optic nerve (upper left), the innermost layer of the retina is thick. In patients with glaucoma (lower left), this layer becomes thin. You can also see a space known as the "cup" growing deeper as the optic nerve is damaged by glaucoma.}
\end{center}

\begin{center}
\textbf{A healthy optic nerve is made up of about 1 million optic nerve fibers (upper right). As glaucoma progresses (lower right), the number of nerve fibers is reduced and the optic nerve becomes much narrower.}\textsuperscript{25}
\end{center}


\textbf{The Glaucoma Working Group suggests the following actions for diagnosed patients:}

3. A Refresher on Pressure
Eye pressure readings are an important way to monitor the progression of your glaucoma. Your ECP may check your pressure using a quick puff of air directed at the eye, or by gently applying a pressure-sensitive tip to the eye.\textsuperscript{26} Numbing drops may be used to make this test more comfortable. Ask your ECP how often you should get your pressure checked and which test is best for you.
It’s important to understand that eye pressure can fluctuate (go up and down) throughout the day and from one visit to the next, so you must get tested regularly to get an overall picture. Think of your eye pressure as a movie made up of many still images. With just one or two images, you don’t get the whole story. But with many images in succession, you can tell what’s going on.

4. Make it Personal
If you’re in your 40s, 50s, or 60s, you may find yourself juggling the needs of elderly parents with the needs of teenage or young adult children. It can be hard to find time for yourself and your own health. But if you have glaucoma, it’s important to find a way to make eye health a priority.

Work with your ECP to develop a tailored disease management plan that fits your individual lifestyle and routine. Your ECP may recommend prescription eye drops, laser treatment, or other types of surgery. While these treatments may help reduce high eye pressure, they do not improve sight already lost because of glaucoma.

Consider the factors in your life that may affect your ability to adhere to your plan, including taking the medication, refilling prescriptions, and scheduling follow-up visits, and try to address these factors as you develop your personalized plan. If you’re still having trouble with adhering to the treatment plan or administering medication correctly, tell your ECP, so he or she can fully understand the issues you are having and address them. You can also ask another practitioner within the office for help.

5. Somebody to Lean on
Remember that family, friends, patient support groups, and your ECP can be important sources of support in managing your glaucoma. Here are some ways you can lean on your support system:

- Bring a family member to your eye exams to help listen and ask questions
- Ask your ECP office to send you reminder notices about upcoming appointments
- Ask a loved one to help you adhere to your treatment plan, which may include administering your medication, if you are having trouble
- Join a glaucoma support group online to learn how other patients manage their disease
Acknowledgements
The Glaucoma Foundation, the Alliance for Aging Research, and Merck would like to recognize and thank the expert members of the Glaucoma Working Group for their contributions:

Scott R. Christensen  
President & CEO, The Glaucoma Foundation

Daniel P. Perry  
President & CEO, Alliance for Aging Research

Gregory K. Harmon, M.D.  
Chairman of the Board, The Glaucoma Foundation; Voluntary Faculty, Weill Medical College of Cornell University, New York Presbyterian Hospital

James C. Tsai, M.D.  
Chair, Medical Advisory Board, Robert R. Young Professor and Chairman, Department of Ophthalmology & Visual Science, Yale School of Medicine

Paul Kaufman, M.D.  
Chair, Department of Ophthalmology and Visual Sciences, University of Wisconsin Madison

We also wish to acknowledge The Glaucoma Foundation Medical Advisory Board for its careful review of this content.

The information provided in this document is not intended to be a substitute for professional medical advice. Please consult your health care provider directly with any questions you may have regarding your health, condition, or treatment. Your health care provider should be your primary source of information regarding your medical condition and treatment.

This document and its contents are intended for use by U.S. residents.

TAKE On Glaucoma: Take Action to Know your Eyes
This declaration is part of the TAKE on Glaucoma: Take Action to Know Your Eyes campaign, which was developed by The Glaucoma Foundation, Alliance for Aging Research, and Merck with insight from the Glaucoma Working Group. The campaign aims to educate Americans about eye health, particularly glaucoma, so that the disease is detected early and managed properly for every patient. The TAKE on Glaucoma website houses educational information about glaucoma as well as an interactive quiz and downloadable tip sheets to help patients and caregivers better understand the disease. Visit www.takeonglaucoma.com to learn more.

TAKE on Glaucoma is an educational program developed, in partnership, by The Glaucoma Foundation, the Alliance for Aging Research, and Merck, and is funded by Merck.
References