



OUTSIDE THE OFFICE

Access to support and education beyond their scheduled visits can provide the comfort that patients need.

BY JAMES C. TSAI, MD, MBA



Because open-angle glaucoma often produces significant damage and vision loss before the disease is detected, recently diagnosed patients may exhibit shock, anger, depression, stress, fear, and/or resignation. Although physicians and their staff provide valuable disease-specific information and support, patients' needs do not end with their visit to the office. Fortunately, medical organizations, foundations, and patient support groups offer this assistance, and a vast array of medical information is also available on the Internet.

THE AMERICAN ACADEMY OF OPHTHALMOLOGY



www.aao.org

The American Academy of Ophthalmology's (AAO's) website contains a wealth of information about glaucoma and resources for both practitioners and patients. Through the assistance of nearly 7,000 volunteer ophthalmologists, the AAO's EyeCare America program has offered medical eye examinations—often at no out-of-pocket cost—to 1.8 million individuals since 1985. The EyeSmart public awareness campaign, sponsored by the AAO, has proven to be a trusted source of accurate, timely, and relevant health information.

THE AMERICAN FOUNDATION FOR THE BLIND AND PREVENT BLINDNESS



www.afb.org and www.preventblindness.org

Both the American Foundation for the Blind and Prevent Blindness are dedicated to advocating for public policies that improve eye care services and enhance patients' access to them. These nonprofit organizations also provide useful information about eye disease, eye health, and eye safety.

THE AMERICAN GLAUCOMA SOCIETY



www.americanglaucomasociety.net

Through its website, the American Glaucoma Society (AGS) offers numerous resources for patients' education and support. A new public service program of the AGS Foundation, AGS Cares, is dedicated to providing surgical glaucoma care by volunteer

ophthalmologists at no additional cost to uninsured patients who qualify for such treatment.

THE INTERNATIONAL GLAUCOMA ASSOCIATION



www.glaucoma-association.com

In the United Kingdom, the International Glaucoma Association is a charitable organization focused on helping people with glaucoma by providing insightful information, literature, advice, and educational programs.

THE NATIONAL EYE HEALTH EDUCATION PROGRAM



www.nei.nih.gov/nehep

The National Eye Health Education Program of the National Eye Institute helps health and community professionals build public awareness about eye health, thereby reaching populations at elevated risk of ocular disease and vision loss. The website provides free downloadable educational toolkits (eg, PowerPoint presentations, Glaucoma Fact Sheet, Glaucoma Eye-Q tests) for practitioners to use during educational sessions on glaucoma in their communities. To facilitate communication, most of the educational materials and training tools are available in both English and Spanish.

PRIVATE FOUNDATIONS



www.glaucomafoundation.org and

www.glaucoma.org

Two mission-based, privately funded foundations dedicated to supporting groundbreaking research in glaucoma and educating the public about the disease are The Glaucoma Foundation and the Glaucoma Research Foundation. Both organizations are exemplary in the scope of the educational materials and support that they provide to patients and health care providers (at little or no cost). Their websites are full of useful educational materials to be downloaded or ordered that are designed for patients facing all the challenges of living with glaucoma. An excellent example is the free booklet "Understanding and Living With Glaucoma," which patients may order on the Glaucoma Research Foundation's website. Also highly useful is the electronic booklet, "Doctor I Have a Question," a guide for patients and their families that is available on The Glaucoma Foundation's website.



SUPPORT GROUPS



Individuals afflicted with a blinding disease such as glaucoma may benefit substantially from the support of fellow patients, physician specialists, and counselors. These in-person and online groups create multiple forums where patients can share their stories and discuss their experiences. For example, the Glaucoma Support and Education Group (New York Chapter of The Glaucoma Foundation) meets monthly at New York Eye and Ear Infirmary of Mount Sinai. During these Saturday morning meetings, patients gather to learn about and discuss innovative new approaches to glaucoma diagnosis and management with leading experts in the field. The New England Chapter of The Glaucoma Foundation holds free educational and informational meetings for individuals with glaucoma and their family and friends at the Massachusetts Eye and Ear Infirmary.

The Glaucoma Research Foundation's website also has links to several online glaucoma support groups, including the Glaucoma Service Foundation to Prevent Blindness in Philadelphia (offering an online glaucoma chat room as well as in-person meetings at the Wills Eye Hospital). In addition, Internet and social media companies offer many online support groups for glaucoma patients and their families. For example, Yahoo! hosts disease-specific groups such as "Adult Patients Under Pressure" and "YUP Parents" (for family members raising a child with glaucoma), and Facebook offers "Glaucoma Eyes" and "Glaucoma Support."

On both organizations' websites, patients may sign up to receive electronic newsletters, which provide timely advice and information on diagnosis, treatment, and research advances in glaucoma.

CONCLUSION

Patients afflicted with visually significant and/or refractory glaucoma often feel overwhelmed by the challenges and limitations of a blinding disease. Patients and their eye care providers can benefit from the growing and varied information available in print, online, and in support groups. ■

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