Eye to Eye

Spring 1997

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Living With Glaucoma
As Told to Annette Golia

When I found out I had narrow angle glaucoma, my first thought was "Who will take care of my children if I go blind?" I am only 31 years old, and I have two young daughters at home. I then reflected back to 1982 when, at the age of 41, my mother was diagnosed with the same condition. I remember how she despaired over the possibility that she might lose her eyesight before my high school graduation. It was her experience that had compelled me to find out about my own situation so early in my life.

I was a senior in high school when my mother returned home from the eye doctor with a very upsetting diagnosis. She had been told during a routine exam that if she didn't have surgery immediately she could go blind from narrow angle glaucoma, a form of glaucoma that is hereditary. Our lives changed after that day. With my father at her side, my mother searched for a cure for her condition. It was a very trying time for all of us. We were scared and worried about my mother. Our love and support of one another got us through the ordeal, and with the help of some excellent doctors, my mother's eyesight was saved. Our family never forgot the experience and my parents made their three children promise that we would see our eye doctors regularly to be screened for glaucoma.

At my first screening at age 27, I was diagnosed with high intraocular pressure. Surgery was not recommended because I was pregnant at the time. Subsequently, I was scheduled to have regular check-ups with ophthalmologists to monitor the pressure. With two small children at home, I must admit there were times that my mother had to keep after me to make sure I didn't miss any doctor's appointments. Her diligence - and mine - proved to be worth the effort. Four years after my first screening, I was told I did indeed have the same condition as my mother - narrow angle glaucoma. I also found out that, like my mother, I have a plateau iris, and like my father, I have iris cysts which can complicate glaucoma.

These conditions were alleviated through numerous laser surgeries. I was very fortunate that my diagnosis was made early, and no damage to my eyesight occurred. Today, I lead a completely normal life. I don't use eye drops right now and my situation is not considered dangerous. But, in the back of my mind, I know that could change at any time. I am conscientious about seeing my doctor every three months to make sure that my condition remains stable. My family's support and my mother's experience have helped me get beyond the fear and depression I initially felt. And, I have great faith in my doctor who assures me that he can "fix anything."

At the time of my mother's ordeal, no one in my family was very familiar with glaucoma. And, we certainly had never heard of narrow angle glaucoma, a less common form of the disease. Now, out of necessity, we've become "experts" on the subject. There are times when I ask: "Why me? Why did I inherit this disease?" But, I know there is no answer. My two other sisters have been screened for glaucoma and, although one has slightly elevated pressure, they do not have any signs of glaucoma. My father has been diagnosed...
and treated for open angle glaucoma, a more common form of the disease that is usually associated with aging.

My mother's story appeared in this newsletter last year (Spring, 1996, Volume 7, Number 2). She is referred to by her doctors as "the very lucky lady." I guess you could say that I am her "very lucky daughter." My hope is that my two daughters will be even luckier. I am optimistic that in the future a cure for glaucoma will be found, and no one will have to worry that they will lose their eyesight to this disease. In the meantime, I will make sure my daughters get regular eye exams because of the importance of early detection.
Q: I'd like to know whether it is recommended to do a corrective procedure for glaucoma independently of a cataract correction. How successful is this kind of procedure? Also, what are some of the long-term effects of continuing use of medication such as Pilocarpine? I've been told that it becomes more and more difficult to dilate the eyes. Are there any "natural" approaches to reduce problems due to glaucoma and/or cataracts, which are considered effective by medical research groups, such as vitamin therapy?

A: Glaucoma and cataracts often occur together. Since glaucoma surgery can only prevent further vision loss due to glaucoma, many patients undergo combined cataract and glaucoma surgery to reverse the vision loss due to cataract. The decision to do combined surgery should depend on the severity of the glaucoma, preoperative intraocular pressure control, number of preoperative medications, the type of glaucoma, and the visual disability caused by the cataract. Fortunately, combined cataract and glaucoma surgery is often highly successful.

Long-term pilocarpine therapy can cause adhesions (scar tissue) between the iris and lens of the eye, which results in the characteristic small pupil seen in many patients with glaucoma. This small pupil often cannot be dilated. In general, physicians make decisions about the use of a particular medication based upon its benefits when compared to its potential risks. If an individual can tolerate the occasional blurring of vision associated with Pilocarpine therapy and this drug successfully lowers the intraocular pressure, most physicians would opt for its continued use. On the other hand, medications which prove to have significant side effects should be discontinued.

Although there is no scientific proof that holistic forms of treatment, including vitamins or herbs, affect the course of glaucoma or the development of cataracts, it is always important to remain in good general health. This is especially true if one suffers from diabetes or hypertension, which are known to affect the eye. - JML
**Q:** I read somewhere that beta-blockers are useful as a calming agent in cases of stage fright, for example, but, the article said they can be especially dangerous for diabetics, asthmatics, and people with glaucoma. Now, of course, this has set me to wondering as I have been using Betagan 0.5% once a day for a few years, prescribed by my ophthalmologist. Is this true?

**A:** Although the article you read is correct in regard to the fact that systemic beta-blockers may be helpful in the short-term reduction of anxiety, beta-blockers are not "dangerous for patients with glaucoma." Beta-blockers can have a variety of untoward effects including slowing of the heart rate (bradycardia), cardiac arrhythmias, congestive heart failure and bronchospasm. Insulin-dependent diabetics should use beta-blockers cautiously, since they may be prone to episodes of low blood sugar, or hypoglycemia, and beta-blockers prevent the reflex physiologic increase in heart rate. The side-effect profile of topical beta-blockers is similar to their systemic counterparts, and patients should always practice punctal occlusion to reduce systemic absorption and enhance ocular absorption. Of note, patients using systemic beta-blockers may have a reduced response to topical beta-blockers. - DG

**Q:** In a previous issue of Eye to Eye in "Doctor I Have a Question," it was stated that if one thinks the medication used is causing side effects, then one should stop using the medication for a while to see if indeed that is what is causing the side effects, whatever they are. But, what medication is one to use to keep the glaucoma in check during the intervening time? Suppose it takes five or six days to determine, does one not use anything?

**A:** Most patients can safely suspend a medication suspected of producing untoward effects for approximately one to two weeks. Your ophthalmologist may suggest that you return sooner based upon the amount of damage to your optic nerve and the level of your intraocular pressure control. Depending upon the particular class of medication, it may take one to four weeks to completely "wash out" the drug effect. - DG

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Q: I have been using Pilocarpine to control IOP for 28 years. Over this long span of time the recovery period has slowly increased from about 45 minutes to almost 4 hours. I am referring to the span of time required for my pupils to restore to normal size and therefore my vision to return to normal (for me that is). This has placed great restrictions on my activities. Is this increasingly long recovery period to be expected with long term use of this medication? Is any harm being done to staying on this treatment for so long? I also use Betoptic once a day. Is there a recommended replacement for Pilocarpine? It does lower my IOP but I'm getting both frustrated and concerned about staying with this treatment so long.

A: There are three new types of ocular antihypertensive medications which have been introduced within the last two years: dorzolamide (Trusoptª), latanoprost (Xalatanª), and brimonidine (Alphaganª). Although each has specific benefits and side effects, they do not reduce pupil size and generally do not produce the same degree of visual diminution/blurring as does pilocarpine. Your complaints are a commonly reported side-effect of pilocarpine therapy and you may consider discussing these newer medications with your physician. Alternatively, you could try a different pilocarpine delivery system such as an ointment (Pilogelª) or slow-release disc (Ocusertª). - DG

Q: I've had glaucoma for several years in both eyes and my right eye has only partial vision. Suddenly the left eye has deteriorated and the doctor prescribed Xalatan. He is not my regular doctor who is away. I've only had drops for 4 days and have burning itchiness and aching and real dryness of the eye and mouth. Can you tell me if this is usually a condition that will go away as I get used to the new drops?

A: The most common side-effects of latanoprost (Xalatanª) are stinging/burning related to corneal irritation, conjunctival injection (redness), and in some patients a darkening of the iris color. Your complaints may represent either a side effect or allergic reaction to this medication (which contains twice the amount of preservative than most anti-glaucomatous medications). Both of these are unlikely to disappear on their own. Latanoprost allergy/ intolerance is not uncommon and may occur in as many as 5% of patients who are currently using other classes of anti-glaucomatous medication. As always, call your doctor if you have an adverse reaction to any medication. - DG
DO YOU NEED INFORMATION?
Send us an email, 24 hours a day, 7 days a week at
glaucomafdn@mindspring.com
We respond within 3 business days.
From the Desk of the Executive Director

"THANK YOU FOR CALLING"

Would you believe that our live operators have had more than 5,000 opportunities to say those words since our last newsletter was published?

Yes, our phones have been ringing off the hook, and we have been thrilled to have the chance to speak, one on one, with so many people from around the United States and the world (our constituents now hail from fifty-one countries).

We are getting all these phone calls, of course, because of our major campaign to bring to the public's attention, via television, radio, newspapers and magazines, the services available on our hotline, 1-800-GLAUCOMA (1-800-452-8266), which is toll-free worldwide. Those services, all free of charge, include the following:

- Assistance with medical referrals: If you don't know an eye doctor in your area, we can give you names, addresses and phone numbers of glaucoma specialists. If there are no glaucoma specialists in your area, we can give you names of other eye doctors. Our database is worldwide.
- Literature: Callers to our hotline receive a copy of our 20-page color brochure, "Doctor, I Have a Question," which explains, in plain language, the basics of glaucoma, and the diagnostic tools and treatments available. In addition, the packet we mail to every caller includes the latest issue of this newsletter, a fact sheet with an overview of the disease, and instructions on how to properly insert eye drops.
- Answers to questions: Many of our callers have specific questions about the disease, the medications, and the surgical procedures used. Our staff is trained to answer most questions. When necessary, we consult with a physician on our Board of Directors to obtain accurate responses. We cannot, of course, give medical advice.

As a result of the high level of interest that members of the public have shown recently in glaucoma, our mailing list has grown by 5,000 in just three months. Since prevention of blindness is such an important goal of our program, and awareness is the key to prevention, we want to reach out to as many people as possible.

Do you have a suggestion as to how we can tell even more people about the services available through our 800 number? Please let us know. The call is free. Thanks.
It is only April, and 1997 has already been a banner year for glaucoma research. A gene that is responsible for autosomal dominant juvenile open-angle glaucoma, and some cases of adult onset primary open-angle glaucoma, has recently been identified. This research promises to lead to major advances in the detection and treatment of glaucoma.

The discovery was made by scientists at the University of Iowa, located in Iowa City, and published in the journal Science on January 31, 1997. This research was led by Drs. Edwin Stone and Val Sheffield, both Associate Professors of Ophthalmology, and Wallace L.M. Alward, Professor of Ophthalmology.

Dr. Robert Ritch, Professor and Chief of Glaucoma Services at New York Eye & Ear Infirmary, stated that "This discovery represents one of the major breakthroughs in the history of glaucoma research. Now we will be able to develop blood tests to determine who is susceptible to this form of glaucoma. The next step will be to look for new ways to approach treatment through modulating the abnormal protein or even the gene itself."

**Scientists identify chromosome and gene mutations**

Three years ago, the University of Iowa researchers linked juvenile open-angle glaucoma to a chromosome, named chromosome 1. Juvenile open-angle glaucoma is a subset of primary open-angle glaucoma that occurs at an earlier age and is often strongly hereditary. There were several possible glaucoma-causing genes that "mapped to," or were found in, this region of chromosome 1. The researchers discovered that the TIGR gene, in particular, existed in the region of chromosome 1 and was known to play a role in the trabecular meshwork and the ciliary body of the eye, both of which affect intraocular pressure.

By conducting further research into the gene mutations at this specific area of chromosome 1, the University of Iowa scientists discovered three different TIGR gene mutations. Dr. Sheffield explained, "At that point we could say that this gene causes a type of inherited glaucoma in families in which the disease gene can be shown to map to chromosome 1. But perhaps this is only one-tenth of one percent of all glaucoma. So the next step was to determine if the gene was also mutated in some unrelated patients with glaucoma."

Dr. Stone explained the results of the following research, which found that fully 3 percent of unrelated patients with glaucoma had one of the three TIGR gene mutations. "These findings suggest that this gene plays a role in a portion of all primary open-angle glaucoma. When you consider that glaucoma affects between 2.5 and 5 million people in the United States, the 3 percent we found in the unrelated group suggests that mutations in the TIGR gene cause glaucoma in more than 100,000 people." Dr. Alward has
characterized this discovery as being the first dent into breaking down the impenetrable mountain that is glaucoma.

**What does this mean for the future of glaucoma treatment?**

Researchers will be better able to understand the disease now that the gene that causes some cases of glaucoma has been found. This in turn could lead to better treatments. Dr. Alward stated, "Open-angle glaucoma can be treated with existing drugs or surgery in most cases. Discovering specific glaucoma-causing mutations will make it possible to identify patients at risk for this disease before significant visual loss has occurred."

"These study results point to the potential availability of a blood test that can identify people at risk" for this type of glaucoma, said Dr. Thomas Weingeist, Professor and Head of Ophthalmology at the University of Iowa. As a result, potential glaucoma victims may be identified earlier, treated earlier, and most importantly, may be spared visual field loss. The Glaucoma Foundation, which funded a portion of this work, will continue to follow this research and will continue to fund such promising work in the field of molecular genetics.
What to Expect When You Visit the Eye Doctor

By Robert Ritch, M.D., Medical Director, The Glaucoma Foundation and Professor and Chief of Glaucoma Service, New York, Eye & Ear Infirmary

One of our readers recently asked what to expect from an eye exam. Since comprehensive eye care and understanding and participation by the patient are critical to preventing blindness from glaucoma, we are pleased to present Dr. Robert Ritch's response to this question: What should a thorough checkup for glaucoma include?

A complete initial routine eye examination should check for visual disturbances, cataract, glaucoma, and retinal disease (macular degeneration, retinal holes or peripheral degeneration). Naturally, the age of the person being examined makes different problems more or less likely. The steps in the examination are:

- Measurement of visual acuity and determination of what corrective lenses, if any, are needed ("refraction"). If 20/20 vision in both eyes cannot be obtained with corrective lenses, an explanation as to why must be sought.
- Testing of eye muscle range of movement (up, down, left, right) and muscle balance and reactions of the pupils to light.
- Measurement of intraocular pressure (fluid pressure) within each eye. Pressure should be measured on anyone old enough to cooperate.
- Slit lamp examination to look for abnormalities of the different parts of the eye, including conjunctiva, cornea, anterior chamber, iris, and lens.
- Gonioscopy: In this test, a mirrored lens is placed on the cornea to examine the angle of the eye. This is especially important in differentiating narrow or closed angles (angle-closure glaucoma) from open angles. In addition, examination can be made of the trabecular meshwork, the sponge-like portion of the eye out of which fluids drain in order to maintain proper fluid pressure. The amount of pigment on the trabecular meshwork can be determined, assisting in the diagnosis of pigment dispersion syndrome (pigmentary glaucoma) and exfoliation syndrome.
- Dilated (ophthalmoscopic) examination of the retina to look for macular degeneration, the optic disc (in glaucoma and some other diseases), retinopathy in patients with diabetes, retinal holes or tears, vascular disease (such as hypertension or atherosclerosis) and other disorders. If the pupils are not dilated, much of this may be missed.

Depending on why the patient has come to be seen, the nature of the patient's complaints, and any problems found, further tests, such as visual fields, photography, or angiography, may be indicated.

In patients with glaucoma, we usually check visual acuity at three-monthly intervals or when the patient comes in, if it is less often than every three months. If the patient complains of decreasing vision (and the doctor relies on the patient to tell the doctor what is wrong or different, if anything is, as best he or she can), then visual acuity, refraction, and visual fields or even more complicated tests, may be necessary. We routinely do a
slit-lamp examination. Periodically (the timing depends on the nature and severity of the glaucoma and the patient's visual status) we perform gonioscopy, visual fields, and a dilated retinal examination.

Knowing this information may or may not prevent optic nerve damage from glaucoma. With the right tests, glaucoma can be discovered earlier and treated more efficiently and successfully. Mistreatment of glaucoma can lead to long-term complications and the loss of sight.

If you do not understand the results of an eye exam, ask your doctor. If you are still not sure, The Glaucoma Foundation can help. Please call our worldwide toll-free hotline, 1-800-GLAUCOMA (1-800-452-8266), for information about glaucoma and physician referrals.
Glaucoma Screening Update

At the event, David Dinkins, former Mayor of New York City, expressed his wish that all people, especially people at increased risk for glaucoma, get regular eye exams.

One principal mission of The Glaucoma Foundation is to advocate for the early detection of glaucoma. Through our literature that is distributed around the world, our public service announcements and press releases, and our 1-800-GLAUCOMA hotline, we work toward making sure that everyone, everywhere, is tested for glaucoma. In addition, we are committed to the Glaucoma Screening Program, in which Foundation representatives and volunteer eye doctors provide glaucoma screenings to different groups. Not only do we detect glaucoma at these screening events, but we also are able to use the statistical results to further publicize the need for glaucoma exams.

On January 22, 1997, The Glaucoma Foundation had the privilege of working with Kirby Puckett, former Major League Baseball player, and currently a spokes-person for Pharmacia & Upjohn's "Don't Be Blindsided Campaign." A public glaucoma screening was held in the mid-town Manhattan YWCA, at which a press conference was held. Participants urged members of the public to get regular exams for glaucoma, the world's leading cause of preventable blindness. In addition, Mark Leeds, Director of the Mayor's Office of People with Disabilities, presented a proclamation from Mayor Rudolph Giuliani.

At the event, David Dinkins, former Mayor of New York City, expressed his wish that all people, especially people at increased risk for glaucoma, get regular eye exams. He stated that African-Americans are more likely to get glaucoma, and that the disease strikes African-Americans earlier than it does Caucasians.

In the case of Kirby Puckett, who lost the sight of his left eye last year at the age of 35, this message rang true. "If I can help just one person, if I can just save one person's sight, it'll all be worth it," stated Puckett. Indeed, three cases of glaucoma were detected at the screening; two of these three people did not know they had the disease. Several screening participants were also found to have suspicious results. Three people were identified as having exfoliation syndrome, one person was identified as having pigment dispersion syndrome and two people were diagnosed with ocular hypertension, all conditions which can lead to glaucoma.

In addition to Mr. Leeds and former Mayor Dinkins, other speakers at the event included: Steven Obstbaum, M.D., President of the American Academy of Ophthalmology; Robert Ritch, M.D., Chief of Glaucoma at The New York Eye & Ear Infirmary and Medical Director of The Glaucoma Foundation; and Daniel Watts from Pharmacia & Upjohn, Inc. The presentations were well-received, and many news stations broadcast stories about the event.

The Glaucoma Foundation is especially grateful to the volunteer physicians who staffed the screening event and helped provide a tremendous service to the public. The
physicians who attended this event were Gregory K. Harmon, M.D., Patricia McLaughlin, M.D., and Joanne Crenshaw, M.D., of the New York Hospital-Cornell Medical Center Department of Ophthalmology; Robert Ritch, M.D., David Greenfield, M.D., and Daniel LaRoche, M.D., of New York Eye & Ear Infirmary Glaucoma Service; and Andrea Katz, M.D. of the Manhattan Eye, Ear and Throat Hospital Department of Ophthalmology. Without their services, this event would not have been possible.

The Glaucoma Screening Program also held a screening at GE/NBC at 30 Rockefeller Plaza in New York City on January 24. The program is growing rapidly, with over 35 volunteer physicians agreeing to donate their time and services, and with many more screening events planned throughout the year.
Making Progress Toward A World Without Blindness

by Michele M. Burnett
Director of Development,
The Glaucoma Foundation

With all the exciting events in the areas of glaucoma research and public education, I am pleased to report that our friends and supporters are becoming more involved as well. Contributions for glaucoma research are on the rise. Recently, three individuals in particular have helped to build the future of The Glaucoma Foundation by becoming members of The Legacy Society. (For our new readers, The Legacy Society recognizes those individuals who decide to make deferred gifts to The Foundation by means of a bequest or other planned gift.)

The search for cures and the need for expanded public outreach continues. Contributions and commitments like these are important if we are to achieve our goal of a world without blindness. If you would like to become a partner in our efforts, please call me at (212) 504-1902 or 1-800-GLAUCOMA.
A Thank You to Our Donors

The Glaucoma Foundation gratefully acknowledges the following individuals, corporations and foundations who have made substantial contributions to support our many programs since December 1, 1996. We appreciate the support of all of our donors and will continue to acknowledge their support in each issue of Eye to Eye.

- The Alcon Foundation
- Sylvan Coleman Foundation
- Ms. B.G. Deming
- Elmwood Charity Fund, Inc.
- Mr. D.F.K. Finlay
- Mr. Alvin Dworman
- Mr. Frederick W. McCarthy
- Mr. & Mrs. Michael R. McClintock
- Pharmacia & Upjohn/Sweden
- Miss Ethel Sohlberg
- Mr. & Mrs. Richard Spring
- Storz Instrument Company

The Legacy Society

The Glaucoma Foundation pays special tribute to the following individuals for their foresight and generosity in making planned gifts to The Foundation since December 1, 1996:

- Estate of George Greene
- Estate of Marjorie E. Rothenberg
- Estate of Pauline Steinberg

Tribute Gift Program

The Glaucoma Foundation is pleased to acknowledge the following Tribute Gifts that were received since December 1, 1996. These gifts not only provide valuable financial support for The Foundation's many projects, but also recognize the special individuals in the lives of our donors.

Gifts Honoring Special Occasions

Robert Ritch, M.D. from Dr. & Mrs. Phillip Brenner

Gifts Received in Memory of Those Who Have Passed Away
Samuel Bacon, Jr. from Mr. & Mrs. Russell M. Jamison; Mr. & Mrs. Paul Koch; Mr. & Mrs. Allan J. Lewis; Mr. & Mrs. Charles F. Litz, Jr.; and P&N Distribution Corp. 
Mrs. Clavis from Mr. & Mrs. Hubert J. Biehle 
Ruth Corwin from Michele M. Burnett; Frances Goldenberg; Dr. & Mrs. Jeffrey M. Liebmann; Erin Martineau; Dr. & Mrs. Thomas O. Muldoon; Mr. & Mrs. Sheldon M. Siegel; and Doris Weinstock 
Caroline Czerwiecki from her son, John J. Czerwiecki 
Wallace Hurst, Sr. from George Cohen 
Fannie & David Kleinman from Mr. & Mrs. Herbert Inselberg and Mr. & Mrs. Sheldon M. Siegel 
Horace S. Volz from Pattyson-Cape Cod Property

To receive a Contribution Package, a Tribute Gift Program Package or to make a donation by phone, please call The Foundation's Development Office at (212) 504-1902.

In order to locate additional supporters for The Glaucoma Foundation, we occasionally trade mailing lists with other non-profit groups. If you prefer not to receive mailings from other groups, please check the box on the coupon on this page and return it to The Foundation. Thank you.

To Receive a Tribute Gift Program Package or to make a Tribute Gift, please call The Foundation's Development Office at (212) 504-1902 or 1-800-GLAUCOMA.
Dear Sirs,

Many thanks to you for your prompt reply to my request for information on glaucoma. As a recently diagnosed glaucoma patient, I really appreciated your clear, comprehensive overview of this eye disorder.

The brochure and other enclosures answered so many of my questions. It put my mind at ease regarding the options open to me for treatment and gave me a foundation of knowledge upon which I could draw during discussions with my ophthalmologist.

Please keep up the good work!

Gratefully yours,
Dorothy J. Evenden

To Whom It May Concern:

In your last newsletter you made a tribute to a lady who is 83 and blind from glaucoma. I feel that this was a very depressing article for anyone who has glaucoma.

We all hope that we will not go blind and to see that it did happen to someone at the present time is very disturbing.

I wish you could have mentioned how long this lady had glaucoma and how it progressed to blindness.

I am glad this woman has the courage to go on even though she is blind, however everyone else is not so strong.

I have always looked forward to your newsletters, however this had me so upset I am almost afraid to read any future newsletters.

Thank you.
Anonymous

It is not our intention to make anyone with glaucoma fearful of their situation. Mrs. Adair lost her sight gradually over a ten-year period. In telling her story, we hope to encourage others to visit the eye doctor for regular exams so that blindness from glaucoma can be prevented. We hope you will continue as a reader of "Eye to Eye." - ed.
Calendar of Events

August 11, 1997
- Monday -

Third Annual Glaucoma Golf Classic
Nassau Country Club
Glen Cove, Long Island
212-504-1902 for information

December 4, 1997
- Thursday -

11th Annual Black & White Ball
Silent Auction/Raffle
World Financial Center Winter Garden
212-504-1902 for information