

E U E T O E E

THE
GLAUCOMA
FOUNDATION
NEWSLETTER

SPRING 2008

It's especially important for glaucoma patients to follow-through with their treatment plans – even while traveling. Here's a checklist from The Glaucoma Foundation to help you prepare for a safe and healthy trip:

Are Your Rx's Ready for Summertime Travel?

- Make a list of all medications you normally use, noting each prescription dosage, the medication's trade name as well as the generic name of the drug. Generic names are especially important if you are traveling out of the country where drug makers may use different names from those in the United States.
- Bring a sufficient supply of each medication for the length of your trip and talk to your doctor in advance about getting extra prescriptions just to be safe.
- Pack your medications in their original drugstore containers rather than in pill cases or other unlabeled bottles.
- Never pack your medications in checked baggage which can be lost or stolen. Put them in your carry-on bag and always keep that with you.
- Store all medications in a dark, cool area – for example, among or inside clothing.



► Start your trip with new refills of your medications. Glaucoma patients who refrigerate their eye drops out of choice rather than necessity should remember that refrigerators are uncommon in hotels. Beginning a new bottle will prevent you from altering the regular temperature of an open medication.

► If you're crossing several time zones, ask your doctor how you should take your medication. Many doctors recommend adapting your schedule to the local time at your destination and not

worrying about a missed dosage due to time changes. This can simplify your regimen during your stay as well as upon your return.

And here are a few final eye care travel tips:

- Traveling on a plane will not affect your eye pressure (IOP) – it is a controlled atmosphere and compensates for changes in altitude. But open medication bottles carefully after you've landed.
- The air on airplanes is very dry. If you wear contact lenses, frequently apply rewetting solution.

Bon Voyage!

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Scott R. Christensen

Letter from the President

Dear Friends:

The opportunity to participate in the first-ever World Glaucoma Day on March 6 was exhilarating. There is no question that the entire experience was productive for The Glaucoma Foundation as well as for the broader glaucoma community.

A joint global initiative of the World Glaucoma Association and the World Glaucoma Patient Association, World Glaucoma Day's goal was to increase awareness of the disease through hundreds of activities planned around the world. Indeed, more than 600 educational and screening events took place from Buenos Aires, Argentina to as far away as Gulistan, Uzbekistan.

In the United States, in addition to local screenings and patient support activities, there was a determined focus on visiting Capitol Hill offices in Washington, D.C. The purpose was to educate federal lawmakers and their staff members about the high incidence of glaucoma, the need for early detection and treatment and most critically, increased governmental funding of vision research. To highlight the message about early diagnosis and treatment, Congressional staff members participated in a screening event. As you will read, we anticipate positive reverberations from these and the other meetings that transpired.

We are also delighted to report that during that same week, The Glaucoma Foundation, along with the Glaucoma Research Foundation, were honored by each receiving the prestigious American Glaucoma Society's President's Award. This honor recognizes the important research and educational work that comprise the mission of TGF. We are pleased to share this award with you, our valued friends and generous donors, who make our programs possible.

Our efforts simply could not be achieved without the support of so many individuals. Thanks to your ongoing generosity, we will be allowed to continue our efforts to eliminate preventable blindness from glaucoma. We extend our heartfelt thanks to each and every one of you.

Sincerely,



Scott R. Christensen
President
Chief Executive Officer

Doctor, I Have a Question.

DIHAQ



Questions answered by:

Dr. James Tsai

Robert R. Young Professor and Chair
Department of Ophthalmology and Visual Science
at Yale University School of Medicine

Should glaucoma patients stop participating in yoga, boxing, Pilates, kickboxing or other rigorous fitness classes once diagnosed?

It is generally recommended that upside-down (inverted) yoga positions, scuba diving and bungee jumping be avoided as these activities may cause an increase in IOP. However, if you are concerned about a particular yoga position or exercise class you are taking, please consult your ophthalmologist or general practitioner before starting any new fitness routines.

My ophthalmologist has informed me that I am a "glaucoma suspect." How come I wasn't prescribed eye drops?

A "glaucoma suspect" is typically a person with one or more risk factors (e.g. elevated IOP, family history) that may lead to the development of glaucoma while not currently having any definite signs of glaucomatous damage (i.e. optic nerve damage and/or visual

field loss). Your ophthalmologist may wish to follow you without treatment until evidence of glaucoma is present. Once glaucoma is confirmed, your doctor will then decide on the appropriate course of action (including the institution of IOP lowering therapy).

How come the Xalatan drops I receive from the pharmacy are stored in the refrigerator but the samples from my doctor are not refrigerated?

The expiration date (i.e. shelf life before opening) determines whether refrigeration is required. It is anticipated that the shelf life for the Xalatan drops at the pharmacy will be longer than that for the sample bottles provided by your doctor (and thus refrigeration is suggested for the pharmacy). At home, if you have only one bottle that you are using, it is not necessary to keep it refrigerated. If you have more than one Xalatan bottle on hand, it is a good idea to store the unopened prescriptions in the refrigerator until usage.

New Scientific Advisory Board Member

Ting Xie, Ph.D., Investigator at the Stowers Institute for Medical Research in Kansas City, MO, has joined TGF's Scientific Advisory Board.

His research focus is on the genetic and molecular analysis of stem cell regulation and development in *Drosophila* and mice. Dr. Xie joined the Stowers Institute after completing a Howard Hughes Medical Institute postdoctoral fellowship at the Carnegie Institution of Washington. He received his Ph.D. from the Joint Graduate Program in Molecular Biology

and Biochemistry of Rutgers University and the University of Medicine and Dentistry of New Jersey.

Members of the SAB include many of the most respected glaucoma clinicians and researchers. In addition to shaping TGF's scientific message to the public, many serve on the committee that reviews research applications and makes recommendations to The Foundation's Board of Directors for funding approval.

News from the Glaucoma Community



World Glaucoma Day

March 6 marked the first observance of World Glaucoma Day, a joint global initiative of the World Glaucoma Association and the World Glaucoma Patient Association.

"The day was planned as a truly international observance – with the sum total of local awareness and educational events making a real impact in raising the awareness of glaucoma worldwide," said Scott Christensen, TGF President as well as President of the World Glaucoma Patient Association.

While early detection is the key to treating and halting the effects of glaucoma, current worldwide estimates reveal that more than 50 percent of glaucoma sufferers in developed countries are unaware they have the disease. This number can climb as high as 90 percent in many undeveloped nations.

"Because glaucoma strikes so silently and gradually, it's absolutely crucial to educate people about the value of early detection," said Dr. Robert Ritch, The Foundation's Medical Director and co-founder of the World Glaucoma Patient Association. "Individuals in our country need to be much more vigilant about glaucoma, especially if they fall into one of the higher risk groups," he added.

In New York City, Mayor Michael Bloomberg marked the observance by issuing a proclamation, which said: "Drawing on the collective strength of patient support groups, medical professionals, and glaucoma institutions across the globe, World Glaucoma Day will help countless individuals avoid the preventable vision loss that arises from this prevalent disease. I commend the World Glaucoma Association and the World Glaucoma Patient Association for initiating this crucial public awareness campaign."

Advocacy for Increased Federal Funding

Advocacy Day was one of several events that took place in the nation's capital on World Glaucoma Day. Physicians and others, including TGF's Scott Christensen, made the rounds of nearly 100 Capitol Hill offices to educate members of Congress and their staffs about the incidence of glaucoma and the need for increased vision research funding.

They urged members to support a 6.6 percent increase in Fiscal Year (FY) 2009 funding for the National Institutes of Health (NIH) and the National Eye Institute (NEI).

This increase would result in NEI funding of \$711 million, an approximate \$44 million increase over FY2008, and NIH funding of \$31 million, \$1.9 million over the net program level of \$29.2 million in FY 2008.

Advocates pointed out that a delay in the ability of NEI to provide grants jeopardizes the continuity of research at a time when eye disease and vision impairment are major public health problems growing exponentially due to: an aging population, a disproportionate incidence in minority populations, and as a result of other chronic diseases, such as diabetic eye disease. The FY2008 budget of \$667 million is less than one percent of the \$68 billion annual cost of eye disease and vision impairment.

Awarding researchers seed grants for innovative projects has always been a primary component of The Glaucoma Foundation's program. Traditionally, preliminary data from these cutting-edge investigations have been used to support proposals for larger grants to entities such as the NEI.

But the purchasing power of the NIH/NEI has been eroded by almost 18 percent over the past five funding cycles, says Scott Christensen.

The funding increase requested represents the current biomedical inflation rate of 3.6 percent, plus a 3 percent increase to begin restoring the NIH/NEI purchasing power.

"We have been very hopeful that our congressional visits would have a positive impact on funding levels, so that vital research to find new treatments and eventually a cure for glaucoma can be intensified," said Mr. Christensen at the time.

In recent weeks, both the House and Senate have acted on a FY 2009 Budget Resolution. Congressional efforts to support a 2009 NIH funding increase include a bipartisan House letter to Appropriations leaders signed by 179 members, as well as an amendment to the Senate Budget Resolution, approved by a vote of 95-4, to increase NIH funding.

"Legislative and ongoing advocacy efforts will continue throughout this calendar year," says Scott Christensen. "Our goal is a bill with an NIH increase that both matches inflation and begins to restore NIH's purchasing power."

campus, focused partly on how results from research studies can apply to clinical trials that are used to support the approval of new drugs, devices, diagnostic technologies, and novel therapies for glaucoma.

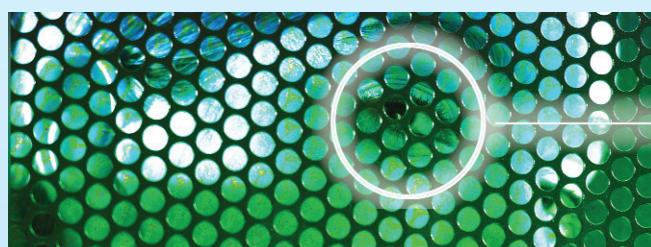
"It was an unprecedented collaborative meeting that hopefully set the stage for bringing new therapies to patients more quickly in the future," said TGF Board Member, Jeffrey Liebmann, M.D., who was a speaker.

Robert N. Weinreb, M.D., who served as Program Co-Chair along with Paul Kaufman, M.D, also a member of The Foundation's Board, agreed that "the glaucoma community made considerable progress," particularly in what they heard from the FDA regarding the possibility of new endpoints in glaucoma clinical trials that may be used to support approvals of the next generation of diagnostic and therapeutic products.

FDA-approved drug and device therapies for glaucoma have focused on reducing intraocular pressure (IOP). But advances in ocular imaging technologies today enable researchers to better detect structural changes in the nerve fiber layer of the retina and the contours of the optic nerve head.

Currently, in clinical trials submitted to the FDA, such structural changes must also show a high correlation with functional changes in vision to assure the clinical significance of a new therapy. But in glaucoma, structural and functional change may not occur in concert. Early disease may be detected primarily by observable structural change; end stage by functional change. Much of the meeting's discussion focused on how these new structural endpoints – rather than IOP – are incorporated into clinical trials.

The hope is that the regulatory process will be flexible to reflect this disparity – especially when considering a new class of neuroprotective drugs that could lessen damage to the optic nerve before it is manifested in visual functional change.



Landmark Meeting Addresses Clinical Trial Issues

On March 13 and 14, many key parties were at the table when the National Eye Institute (NEI) and the United States Food and Drug Administration (FDA)/Center for Drug Evaluation and Research held a Glaucoma Clinical Drug Trial Design and Endpoints Symposium that engaged glaucoma investigators and clinicians in an important dialogue.

The symposium, held on the campus of the National Institutes of Health's Bethesda

CHAPTER CORNER

Upcoming Glaucoma Support and Education Group Meetings:

New York City Chapter

Date: Saturday, May 17, 2008
Topic: Cataract Surgery for the Glaucoma Patient
Speaker: Adriana Gonzalez, M.D.
Location: New York Eye and Ear Infirmary
310 East 14th Street, NYC
Time: 11:00am

Date: Saturday, June 21, 2008
Topic: Reduced Vision? No Problem When You Learn Coping Skills!
Speaker: Tom McCarville, Blind Rehabilitation Teacher
Location: New York Eye and Ear Infirmary
310 East 14th Street, NYC
Time: 11:00am

New England Chapter

Date: Saturday, June 14, 2008
Topic: What Your Doctors Learn from Studying Large Groups of Glaucoma Patients
Speaker: Louis Pasquale, M.D., Co-Director, MEEI Glaucoma Service
Location: Massachusetts Eye and Ear Infirmary
243 Charles Street, Boston, MA
Time: 10:00am

RSVP Required for The New England Chapter Meeting Only—212.285.0080

For more information please call
TGF at 212.285.0080

New England Chapter Update

On Saturday, April 5th, the New England Chapter of The Glaucoma Foundation held its initial lecture for 2008 at the Massachusetts Eye and Ear Infirmary (MEEI). The guest speaker was Gregory Harmon, M.D., Chairman of the Board of The Glaucoma Foundation. He first commented on his book "What Your Doctor May Not Tell You About Glaucoma," and then addressed at length the latest glaucoma treatments and recent advances in glaucoma research.

The overflowing and extremely attentive audience in the Infirmary Board Room consisted of glaucoma patients, their families, practicing clinicians and medical students. Following the presentation, a number of patients took the opportunity to share their experiences and to ask Dr. Harmon questions. Everyone found the lecture to be informative and the discussion and interaction afterwards quite valuable.

The next meeting of the New England Chapter will again be at the Massachusetts Eye and Ear Infirmary, on Saturday, June 14th, when Dr. Louis Pasquale, Co-Director of the Glaucoma Service, at MEEI, will speak to the topic: "What Doctors Learn from Studying Large Groups of Glaucoma Patients."

Anyone who is interested in learning more about the New England Chapter should contact Chapter President, Catherine Duffek, at 617.797.6476 or cduffek@glaucomafoundation.org.



YOUR ANSWERS PLEASE!

We are always interested in your experiences as a glaucoma patient or glaucoma suspect, or as a family member, caregiver or friend of a patient. So, from time to time we will ask you a few simple questions on such subjects as awareness, compliance, counsel from physicians, etc. Your answers will help us carry forward our educational initiatives.

-
1. I am a glaucoma patient..... yes no
 2. I am a glaucoma suspect..... yes no
 3. I do not have glaucoma.....
 4. My age is: under 40 41-50
 51-60 over 61
 5. How did you first learn about the need to get tested for glaucoma?
 General Physician Family Member
 Friend Other _____
 6. Does your general physician discuss eye care with you? yes no
 7. Has your general physician reminded you to get your eyes examined? yes no
-

Please send your answers to:
The Glaucoma Foundation
80 Maiden Lane, Suite 700
New York, NY 10038.

If you prefer, complete the survey
on our website –
www.glaucomafoundation.org
or email your answers to
survey@glaucomafoundation.org

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Glaucoma and Pregnancy

What You Should Know

It's important for a woman with glaucoma to work in close unison with her ophthalmologist and her OB/GYN when she is thinking about having a family. Making a plan prior to conception is the best plan of action. By discussing her plans to become pregnant with her doctors, a concerted effort can be made to achieve intraocular pressure (IOP) control on minimal or no medications, minimizing risk to the fetus while safeguarding the eye.

The biggest risk to the fetus is during the first trimester of pregnancy. Because a woman may not know she is pregnant during these first weeks, it is vital that she meet with her doctors to discuss a plan before she conceives.

Some medications have shown adverse fetal effects in animals. While there have been no large scale controlled trials, there is accumulated experience, so ophthalmologists treat each case individually with the goal of minimizing risks to the fetus.

The goal is to minimize drug exposure to the fetus throughout the pregnancy, especially during the first trimester. The treating ophthalmologist must weigh the potential risk to the mother's vision against the risk to the fetus. Some patients are able to discontinue all glaucoma medications for the first 12 weeks. This might be possible, for example, if a patient is a glaucoma suspect or has early glaucoma with limited optic nerve damage and modestly elevated IOP. Frequent monitoring of the eyes is the key.

In other cases, going off glaucoma medications during pregnancy is not possible, for example if a patient has substantial optic nerve damage or extremely elevated IOP levels and is not able to tolerate uncontrolled IOP even for a short period of time. In these cases, the physician would try to prescribe the fewest possible medications, thoughtfully selected and dosed to minimize risks to the fetus. Additionally, the expectant mother should be sure to use the nasolacrimal occlusion (NLO) technique to minimize the amount of medication that enters the blood stream. (This technique is recommended for all glaucoma patients. When administering the eye drop, press your index finger firmly in the nasal corner of the eye, holding your finger there for 1-2 minutes after the drop has been instilled.)

Sometimes, surgery, such as laser trabeculoplasty, may be the best option for patients who cannot achieve an acceptable IOP level with minimal or no glaucoma medications. If possible, surgical procedures to control the IOP are best performed prior to conceiving so that the IOP level can be controlled and stable throughout the entire pregnancy, especially the first trimester. If necessary, laser trabeculoplasty can be performed during pregnancy. Incisional surgery, such as trabeculectomy, is safest prior to conception. If surgery is required during pregnancy, trabeculectomy is probably safest in the second trimester. In such surgical cases, topical or local anesthetic is preferred.

There is no data suggesting problems with labor and delivery of a newborn. Periods of extreme straining during delivery may raise IOP, but this is very brief. Nursing must be considered as well, and warrants a discussion between the patient, ophthalmologist and the baby's pediatrician. Just as medications may enter the circulation of an unborn fetus when the pregnant woman uses glaucoma eye drops, these medications may also be secreted into her breast milk when nursing. Decisions on glaucoma treatments during the nursing period must be carefully considered to determine what plan is safest for both mother and baby.

And finally, many mothers ask if their glaucoma puts their child at risk for developing the disease. Family history is a significant risk factor for glaucoma. Once a child is old enough to sit still for an eye examination, the child should get tested, and should be retested at periodic intervals thereafter. As the child ages, the frequency of eye exams may need to increase. Be sure to let your child's pediatrician know that you have glaucoma.

American Glaucoma Society Honors The Glaucoma Foundation

The Glaucoma Foundation and the Glaucoma Research Foundation were the 2008 recipients of the American Glaucoma Society's (AGS) President's Award. AGS President, Robert Weinreb, M.D., presented the award to Scott R. Christensen, President and CEO of The Glaucoma Foundation, at the Society's Annual Meeting held in Washington, D.C. on March 7, the day following World Glaucoma Day.

The American Glaucoma Society supports glaucoma specialists and scientists through the advancement of education and research. Recipients of the annual AGS President's Award are chosen by the AGS President and approved by its Executive Committee for "significant contributions to the glaucoma community..." In previous years, distinguished individuals in the field have received this prestigious award. This is the first year that an organization has been so honored with the President's Award.

"We are delighted that The Glaucoma Foundation has been recognized for our ongoing efforts in the areas of glaucoma research and education," says Scott Christensen. "We understand the urgency of making glaucoma research everyone's top priority if we are to unlock the mysteries of this disease. And we are committed to reaching out at home and globally to raise awareness about this disease that afflicts 67 million people around the world."

UPCOMING EVENTS

The 15th Annual Think Tank

September 19-20, 2008

Grand Hyatt
New York, NY

22nd Annual Black + White Ball

December 3, 2008

The Pierre Hotel
New York, NY

For more information on either event contact
The Glaucoma Foundation at 212.285.0080



The Glaucoma Foundation
80 Maiden Lane, Suite 700
New York, NY 10038
www.glaucomafoundation.org
T 212.285.0080 F 212.651.1888

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CHANGE

In Support of Future Research Breakthroughs

Glaucoma Advocacy Day in Washington, D.C. delivered a clear message to members of Congress: their support of increased research funding for the National Institutes of Health/National Eye Institute is crucial as a delay in the ability to provide Federal grants jeopardizes the very future of research. Continued flat funding not only increases competition for grants but can prompt investigators to submit proposals that are less innovative.

For years, The Glaucoma Foundation has awarded seed grants for highly innovative projects that historically have provided data and report results used in proposals submitted for government funding. Future breakthroughs remain totally dependent upon this cutting-edge research.

The prognosis for increased Federal funding in 2009 appears to be promising. Nevertheless, and still needed, is your ongoing support so that we can continue to and hopefully increase the grants we will award to innovative researchers in the year ahead. **Your generosity can help bring us closer to reaching the ultimate goal of finding a cure.**

A copy of The Glaucoma Foundation's annual financial report may be obtained upon request by writing to The Foundation at 80 Maiden Lane, Suite 700, New York, NY 10038 or by residents of the states listed below from the appropriate state agency. Florida: A copy of the official registration and financial information may be obtained from the Division of Consumer Services by calling toll-free within the State .Registration Number - CH7263. Registration does not imply endorsement, approval, or recommendation by the State. Maryland: Information filed under the Maryland Charitable Organizations Laws can be obtained for the cost of postage and copies from the Office of the Maryland Secretary of State, Statehouse, Annapolis, MD 21401 or by calling 410-974-5534. Mississippi: Mississippi Secretary of State's Office, Charities registration, PO Box 136, Jackson, MS 39205-0136, 601-359-1633. New Jersey: Information filed with the Attorney General concerning this charitable solicitation may be obtained from the Attorney General of the State of New Jersey by calling 201-504-6215. Registration with the Attorney General does not imply endorsement. New York: A copy of the last annual report filed may be obtained upon request in writing to the Office of the Attorney General, Department of Law, Charities Bureau, 120 Broadway, New York, NY 10271. North Carolina: A copy of the license to solicit charitable contributions as a charitable organization or sponsor and financial information may be obtained from the Department of Human Resources, Solicitation Licensing Branch, by calling 919-733-4510. Registration does not imply endorsement, approval, or recommendation by the State. Pennsylvania: The official registration and financial information of The Glaucoma Foundation may be obtained from the Pennsylvania Department of State by calling toll free, within Pennsylvania, 1-800-732-0999. Registration does not imply endorsement. Virginia: Official registration and financial information of The Glaucoma Foundation may be obtained from the State Division of Consumer Affairs, Department of Agriculture & Consumer Services, P.O. Box 1163, Richmond, VA 23209. Washington: Registration and financial report information may be obtained from the Charities Division, Office of the Secretary of State of Washington, Olympia, WA 98504-0422 or by calling 1-800-332-4483. West Virginia: West Virginia residents may obtain a summary of the registration and financial documents from the Secretary of State, State Capitol, Charleston, WV 25305. Registration does not imply endorsement.