First-Ever World Glaucoma Week a Success

From March 7 to 13, the world was abuzz with activities planned to raise awareness of glaucoma during the first World Glaucoma Week (WGW), an expansion of the observance of World Glaucoma Day, launched in 2008 by the World Glaucoma Association and the World Glaucoma Patient Association. Hundreds of local initiatives took place in countries circling the globe. They all shared the same goal of raising glaucoma awareness and promoting the need to get tested.

The rationale for the global focus of the observance is very clear. It is estimated that only one-half of those affected with glaucoma in developed nations are aware that they have the disease, and as many as 90 percent of people with glaucoma in underdeveloped countries are unaware of having the disease or have not even heard of glaucoma.

During WGW, screenings, seminars, media events, and many other activities were organized using local resources to reach patients, doctors, and scientists. In Mendoza, Argentina, a book about the disease was distributed, and in Canada, an online DVD on glaucoma and the importance of compliance was viewed by many.

Conferences and symposia proliferated in such countries as Oman, Poland, China, Lithuania and India. There was a bicycle race in Spain and a symposium on pediatric glaucoma in Turkey. The Caribbean coordinator for the observance arranged for a suitcase of assorted first aid and vision aid supplies to be transported to Haiti.

A proclamation by the minister of foreign affairs of the Republic of Indonesia addressed the various activities to prevent glaucoma in Indonesia, including development of eye clinics and hospitals throughout the country and collaboration with professional societies. “The Indonesian government also encourages more research efforts to combat glaucoma and is committed to these efforts,” the proclamation states.

Closer to home, representatives from The Glaucoma Foundation participated in a very broad array of WGW events on the islands of Barbados and Antigua. The week began in Barbados with Kira Zmuda, TGF's Director of Research and Education Programs, previewing the week’s schedule of events in a television interview. TGF President Scott Christensen and Chairman Gregory Harmon, MD, spoke at a special appreciation dinner.
Dear Friends:

Glaucoma awareness and patient support have always been watchwords for our educational efforts.

TGF’s Lunch and Learn program continues and our presence on Facebook and Twitter and other social media is having a real impact. Especially impressive are the numbers and interest of new friends who have joined TGF’s fan page on Facebook this year. Over 300 glaucoma patients have made that connection, often in meaningful ways. You will read the story of two TGF fans in the article about Living with Glaucoma. Some of these same individuals have now joined one of TGF’s three online email support communities that have a total membership of 880 adult patients, young patients and parents of children with glaucoma.

Most recently, TGF was an active participant in the global observance of the first-ever World Glaucoma Week (WGW) in March. The Foundation personally participated in an array of WGW activities in the Caribbean. Here in the US, we joined with others in the vision community as a co-sponsor of a day of events on Capitol Hill, including a presentation that educated a packed room of Congressional staffers about glaucoma and current research.

In this issue you’ll read about TGF’s own research news, with three new grants awarded to scientists based in the United States and Israel, and about our annual Black & White Ball, which raises essential funding for our research program.

All these initiatives would simply not be possible without the support of our friends. The Glaucoma Foundation has a broad and loyal base – with 14,795 donors in 2009! We value your participation in helping us reach our goals and we are exceedingly grateful for the trust you place in our efforts to defeat this vision-threatening disease.

We hope we can count on your continued support.

Sincerely,

Scott R. Christensen
President
Chief Executive Officer
What’s the difference between a glaucoma suspect and a glaucoma patient?

Elevated intraocular eye pressure (IOP) alone does not mean a diagnosis of glaucoma. A glaucoma suspect is a person with normal visual fields but with (1) normal IOPs and slightly suspicious optic nerve(s) or (2) elevated IOPs and normal optic nerves. While vision loss has not been detected, the patient should be monitored closely and/or prophylactically treated to prevent subsequent development of glaucoma. By definition, a diagnosis of glaucoma implies that detectable damage has occurred (either the optic nerve and/or visual field). At this point, treatment is necessary to prevent any further damage or vision loss.

Can you have glaucoma without having increased pressure inside the eye?

In normal-tension glaucoma, sometimes called normal-pressure glaucoma, the IOP is not significantly elevated. The absolute level of IOP may not correlate with the amount of optic nerve damage or visual field abnormality present. However, despite a lack of IOP elevation in normal-tension glaucoma, the optic nerve does have abnormal disc cupping and the visual field test shows vision loss.

Is refractive LASIK surgery safe for glaucoma patients?

During LASIK, there is a brief, but significant, rise in IOP. Glaucoma specialists tend to discourage these elective procedures in patients with known documented glaucoma where any pressure spike (even if transient) could lead to the progression of visual loss. There may be fewer restrictions with the procedure in patients with ocular hypertension (no documented optic nerve or visual field damage), glaucoma suspects, and perhaps early glaucoma. It is important to note that following the refractive LASIK procedure, the central corneal thickness (CCT) measurements are decreased, thereby often leading to a significant underestimation of the true IOP level. The physician must be made aware of a patient’s past refractive surgery history so that the IOP can be adjusted accordingly to estimate a true reading. In addition, topical steroids used in the LASIK postoperative period may lead to IOP elevation in select patients and therefore this needs to be monitored.

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Living with Glaucoma

People deal differently with the curveballs life tosses their way. That’s true in all facets of life, including how glaucoma patients cope with their diagnosis and with the reality of living with a chronic disease. We’ve asked three individuals whose lives have been impacted by glaucoma to share some of their thoughts in the hope that their experiences can inform others.

Ta’Varee celebrated his first birthday on March 10. He’s a beautiful child and a winner in a contest for “America’s Most Photogenic Baby.” He has also had seven surgeries for glaucoma – the first when he was three months old, the most recent in February. Ta’Varee lives with his parents and older brother and sister in Waukegan, Illinois, about an hour’s drive from Chicago, where he is treated for pediatric glaucoma. His mother, Tanya Duffie, noticed something was wrong when he was very young – his eyes were clouded and teared often and seemed sensitive to light. His checkups and treatments to keep his pressures down have been ongoing ever since.

In spite of the surgeries and medications and the patches and eye shield he must wear after surgery, he’s a happy child who seems very much like other children, Tanya reports. “Of course it’s stressful,” she says. “We don’t know how well he will see. He has very large eyes – a symptom of this kind of glaucoma – and I worry that kids won’t understand and will make fun of him. We pray that it works out and we do what we have to do.”

Tanya gave up her job because it was just too hard to maintain a work schedule. But her family is very supportive and Ta’Varee loves his sister and brother, who do a great job of taking care of him. Tanya has been reaching out to get as much information as she can. She made contact with TGF on Facebook and now plans to join YUP Parents, the email support community for glaucoma parents. A current worry: insurance pays for Ta’Varee’s eye drops, but it is hard to insert drops into a one year old’s eyes. You lose about half and insurance doesn’t cover that.

Lee “Sluggo” Carter is a 52-year-old “big biker guy” from Salida, Colorado. He’s been riding for more than 30 years and “lives to ride.” Today he has a second mantra: “Keeping the rest of my sight for the rest of my life.” About four years ago, Lee started to see halos around lights. He went to the person who took care of his eye glasses but the proper diagnosis wasn’t made. “I began having awful bad headaches, bad vision, white-outs and felt sick.
Then, two close calls on my bike convinced me something was really ‘off’.

An ophthalmologist finally diagnosed Lee with narrow-angle glaucoma (also called angle-closure glaucoma or acute glaucoma). “I was afraid I’d go blind and not be able to ride my Yamaha V-Star motorcycle anymore. I lost side vision in both eyes, but we seem to have caught it in time.” Lee had two glaucoma surgeries and a cataract operation and missed two months at work. “I’m seeing really well,” he says.

“I’m a spiritual person and glaucoma has changed the way I think. Our eyes are everything. I get checked every three months and take all my meds. I do exercises to strengthen my eyes and take vitamins. I get my blood pressure checked and stay fit – I’ve lost over 100 pounds!” Last May Lee joined APUP, the online email support group for adults. More recently, he became a fan of TGF on Facebook. Lee’s advice to others: “If you are older and have worn glasses, get checked once a year by an ophthalmologist. Life goes on!”

Debora K. Grobman, Esq., a TGF board member who devotes much of her time raising awareness about glaucoma, was diagnosed with high intraocular pressure (IOP) in 1997. As she explains, she was compliant, had her eyes examined every three months, took her medications, and had visual field tests every other visit. But she never looked at the results of those visual field tests, trusting her physician who assured her that the results were fine.

After changing doctors nine years later, she was horrified to learn that she had normal-tension glaucoma, a type of glaucoma where glaucomatous damage occurs while IOP is in the normal range, and that she had a serious loss of vision in both eyes. “I almost fainted,” she says; “the room started to spin.” And that wasn’t all. Her ophthalmologist gave no assurances that her sight could be controlled. “It was shocking news,” she recalls. A successful New York attorney, she didn’t tell anyone beyond her immediate circle. “I felt I wouldn’t be valued,” she says. “I was terribly depressed.” A year and a half later, in 2007, she retired to do the things she always imagined doing “someday”, facing the fact that “someday” was now.

But, miraculously, her glaucoma is stable. She has had two laser surgeries in each eye and takes three medications. “I’m very lucky, very grateful, and very compliant,” she says. “I do everything I’m supposed to do, and more. I’ll try anything that might lower my IOP, since keeping my pressures below the normal range (at about 7 or 8) is crucial, and the only known treatment for the type of glaucoma I have. Right now I take ginkgo, omega-3 and green tea drops, all reputed to help lower IOP, but not medically established to do so. My message is to do whatever you can, be screened regularly and work in partnership with your doctor, and above all, look at the results of your field of vision tests. They’re not hard to read!”
“I have benefited from the scientific tradition of knowledge and medical practice [my ophthalmologist and surgeon] have carried forward yet another step, a chain of achievements stretching from antiquity to the present moment,” said John Patrick Shanley in his eloquent remarks after receiving The Glaucoma Foundation’s 2009 Kitty Carlisle Hart Award of Merit for Lifetime Achievement.

The occasion was the 23rd Black and White Ball, held on December 2nd in the elegant setting of New York’s Pierre Hotel, with over 300 private and corporate supporters of TGF in attendance. The gala showcased the important work of The Foundation and raised over $600,000 to carry out TGF’s crucial research and education initiatives. The presentation to Mr. Shanley, the award-winning playwright (Doubt), screenwriter (Moonstruck), and screen director (Doubt) was made in Ms. Hart’s memory by her daughter, Dr. Catherine Hart, and her son, Chris Hart.

In recent years, the Kitty Carlisle Hart Award has been presented to New York State Governor David A. Paterson (2008) and Christopher Gardner, subject of the film “The Pursuit of Happyness” (2007).

Mr. Shanley’s remarks can be found in their entirety on the following page.
“I know about social mechanisms. My family’s Irish. When somebody in my family dies, everybody knows what to do. Phone calls are made, food is cooked, arrangements are taken care of. My family is very good at death. If any of you die, please, call me. I will know what to do.

But Life, that’s another matter.

For instance my Health Plan. My Health Plan fell short. It had a wonderful simplicity. My Health Plan was that I planned to be healthy. That way I wouldn’t need any help from you guys or anyone else. When I got diagnosed with advanced glaucoma, my health plan went out the window. I needed help. I needed people. I needed all kinds of people. And they showed up. All kinds of people showed up. They showed up with compassion, experience, medicine and physical skills. A social mechanism was in place that I didn’t even know about, and it came to my assistance.

It is so sweet to be alive. Vision is not a right, nor is freedom from pain, nor the opportunity to live another day on earth. All the experience of life is exceptional. As we know from physics, nothing is truly stationary. Matter is in motion, and so are we.

We are all Cinderellas. None of us truly belong at the ball. Each of us have some specific hour by which we must depart. These fine clothes we wear, this opulent room we now inhabit, the food and drink offered us, all are temporary honors. A few moments after we enter the great and terrible hall of consciousness, it’s already almost time to say goodnight. Many of us feel the brevity of life most especially at this time of year. Auld Lang Syne.

The streets outside remind us that the winter holidays have come again. The lights I see on Fifth Avenue tonight, I see because of our medical profession. Not many years ago, I would have gone blind. I would be more Scrooge than Scrooge himself if I did not thank my ophthalmologist and my surgeon for saving my sight so that I could see Fifth Avenue tonight. It is their achievement that I see. I have benefited from the scientific tradition of knowledge and medical practice they have carried forward yet another step, a chain of achievements stretching from antiquity to the present moment. It is a noble thing to preserve and extend knowledge in service of humanity. It’s a truly noble thing to show up when people need you.

But I’m worried about you guys. It’s your vocation to take care of the physical disabilities of others, and I worry that no one is reciprocating, making certain that your spirits are not dwindling from neglect. The necessary preoccupation you have with the literal flesh invites perhaps starvation of the soul. We’re all in this together, alive for our little bit of time. And as you caution us to pay attention to the state of our bodies, I also want to encourage you to take care of your hearts and souls. Plenty of people with perfectly good eyesight tonight will not be stirred by the holiday lights or even the stars in the sky. There are many kinds of blindness. Please take care of yourselves as you take care of others. I say this in gratitude. Life is as beautiful as it is brief. Enjoy it.”

Remarks by John Patrick Shanley, 2009 Winner of the Kitty Carlisle Hart Award of Merit for Lifetime Achievement
Richard T. Libby, PhD
Assistant Professor, Ophthalmology
University of Rochester Medical School
Rochester, NY

JNK Signaling is Critical for Retinal Ganglion Cell Death after Axonal Injury
Loss of vision in glaucoma is caused by the death of retinal ganglion cells (RGCs) that send information to the brain. Presently there are no widely available treatments aimed at neuroprotection. This means that in many cases, physicians are left with no treatment options to prevent their patients from losing sight. This project aims to determine the molecular signaling pathways responsible for killing RGCs in glaucoma. Identifying these molecules will provide important information about the complexity of the signaling pathways active in glaucoma, indicate which pathways could be targeted for glaucoma therapies, and identify potential genes that could account for the variability in susceptibility to glaucoma.

Irina G. Surgucheva, PhD
Research Assistant Professor
Department of Neurology
VA Medical Center
Kansas City, MO

Protein Aggregation in Glial Cells of the Optic Nerve: Role in Glaucoma
The optic nerve acts like an electric cable with over a million wires and is responsible for carrying images from the eye to the brain. This electric cable is composed of the endings of cells called retinal ganglion cells and another type of cell called astrocytes, which support normal functions of neuron endings in the optic nerve. In glaucoma, patients’ astrocytes die in the optic nerve because of excessive accumulation of abnormal proteins. This project will investigate why these abnormal proteins accumulate in cells. The project also hopes to unveil the mechanisms of death of astrocytes due to the accumulation of these abnormal proteins and to find substances which might prevent their death.

Michal Schwartz, PhD
Professor of Neuroimmunology
Weizmann Institute of Science
Rehovot, Israel

Using Immune-based Strategy to Awaken Dormant Retinal Stem Cells: A Therapeutic Approach to Glaucoma (Renewal Grant)
While there are treatments to lower pressure in the eye, thereby preventing continued damage, there is currently no cure for glaucoma nor any therapy capable of inducing cell renewal in the damaged tissue. It has been suggested that stem cells, which can differentiate to form numerous cell types, could be used to replace nerve cells in the retina damaged by the disease. Stem cells exist in the mammalian eye but are dormant. The first year of this grant was devoted to exploring the reasons that the ocular stem cells are unable to divide and form new nerve cells. In this second year, an immunological approach will be used as a basis for awakening the quiescent stem cell population. The goal is that activation of these dormant stem cells can be developed into a promising therapy for glaucoma.
Cataracts and Glaucoma

A cataract is a clouding of the eye’s natural lens, allowing less light to pass through and blurring vision. It is estimated that cataracts affect nearly 22 million Americans over the age of 40, and that by age 80, more than half of all Americans have cataracts. For many, they are an unavoidable part of aging.

It is very common for glaucoma and cataracts to co-exist. In both conditions the risk increases with age. In addition, there is a risk of developing cataracts or having them progress after glaucoma surgery. And cataracts, when advanced, can trigger angle-closure glaucoma in susceptible individuals. But while vision loss from glaucoma is still irreversible, loss of vision due to cataracts can usually be reversed by surgically removing the lens and implanting a clear artificial replacement intraocular lens.

When a cataract causes reduced or poor vision, with blurring, glare and dimming of sight that interferes with everyday life, it is usually time for surgical intervention.

If the patient in need of cataract surgery also has glaucoma, the doctor must balance many factors to determine when and how aggressively the glaucoma and cataract should be treated. Surgical options are: cataract surgery alone; surgeries for the two conditions performed at different times (i.e. staged surgery usually involving trabeculectomy followed by cataract surgery); and combined cataract/glaucoma surgery.

Cataract surgery alone is a reasonable option when there is a significant cataract, the glaucoma is well controlled with one type of medication that is well tolerated, there is little or no glaucoma damage, and there is unlikely to be further visual field loss if a postoperative IOP spike occurs. In some cases, removing the cataract can result in a lower IOP. Sadly, this is not an easily predictable outcome and one cannot count on having a lowered IOP as a result of routine cataract surgery.

If a patient’s glaucoma and cataract both require surgical treatment, the doctor must decide how to approach these co-existing needs. Among the factors the doctor considers are:

- Amount of visual field and optic nerve damage
- Number of glaucoma medications a patient is taking before surgery
- Whether glaucoma surgery has already been performed in the eye
- Eye pressure before surgery
- Desired eye pressure after surgery
- Tolerance for specific glaucoma medications

Staged surgeries are often used if the patient has advanced cataract and glaucoma that is severe or very poorly controlled by medication alone.

Combined surgery can be well suited for patients whose glaucoma control requires two or more medications, patients with uncontrolled glaucoma that is mild to moderate, patients whose optic nerves are unable to tolerate post-operative IOP spikes and patients unable to tolerate two separate surgeries.

There are also special situations that can impact cataract surgery. Patients with exfoliation glaucoma often have cataracts and it is best to perform the cataract removal earlier rather than later. Another surgical challenge is when patients have small pupils that do not dilate well. The key is that each situation must be assessed individually. As with any surgical procedure, the patient should discuss the risks and benefits of these surgeries with the doctor.
New England Chapter

In December, Lisa McHam, MD, Glaucoma Specialist at Eye Health Services in Quincy, MA, and New England Chapter Board member, talked about trabeculectomy.

Allen Taylor, Director and Senior Scientist, Laboratory for Nutrition and Vision, Jean Mayer USDA, Tufts University, presented current research findings on nutrition and its effects on cataract formation and age-related macular degeneration in January.

In observance of World Glaucoma Week, Catherine Duffek, President and Founder of the New England Chapter, and Dr. Lisa McHam appeared on Quincy Access Television to talk about chapter activities and the importance of early detection and treatment of glaucoma.

Upcoming dates and speaker information will be available on The Glaucoma Foundation website or by emailing cduffek@glaucomafoundation.org.

Chicago Chapter

Some 116 patients attended two support group meetings of the chapter's Madison, Wisconsin Glaucoma Support and Education Group on January 19. Meetings also took place on March 16, when Dr. Julia Agapov spoke about glaucoma surgeries.

March saw the initial meeting of a new support group in the Glenview area of Chicago, at which Dr. M. Gorla spoke about glaucoma medication. Plans are underway to add support groups in Evanston and Chicago, where Dr. Gorla also has offices. If you would like to be involved with the Chicago Chapter, please email kzmuda@glaucomafoundation.org.

New York City Chapter

Chapter Co-President Edith Marks encourages New York area patients to attend the final three lectures of the NYC Chapter, where they can mingle with other glaucoma patients and get great tips for managing their glaucoma. The upcoming programs are:

April 17, 2010 at 11:00 am
Book Party – Glaucoma-Patient to Patient

Edith Marks, author of Coping with Glaucoma, has a new book, Glaucoma-Patient to Patient. Part I explains the different types of glaucoma, diagnosis, forms of treatment, cataract, and the brave new world of genetics and stem cell rejuvenation. Part II concentrates on strategies for coping, including empowering exercises, nutrition, workplace adjustment and much more. Call 1-800-iUniverse to purchase a copy - Royalties go towards glaucoma research.

May 15, 2010 at 11:00 am
Living with Glaucoma – Support Services

June 18, 2010 at 11:00 am
Cataract and Glaucoma

The group’s quarterly newsletter, “Living with Glaucoma,” reprises the lectures and is available. Meetings take place at The New York Eye and Ear Infirmary at 310 East 14th Street, Manhattan. If you would like to become involved with the NYC Chapter, please email kzmuda@glaucomafoundation.org.

World Glaucoma Week continued from page 1

attended by the local medical and pharmaceutical community, and hosted a Lunch and Learn session, open to all. The Barbados observance wound down after a public evening lecture, with 80 in attendance, and a weekend 5K Glaucoma Awareness Walk. Among numerous programs scheduled in Antigua, Scott Christensen participated in a panel at the American University, and appeared on the “Let’s Talk the Nation’s Health” TV program.
New Corporate Board Member

**Tracy M. Valorie**

Tracy Valorie is Senior Director, Worldwide Commercial Lead Ophthalmology, and Glaucoma Asset Lead at Pfizer Inc. She began her pharmaceutical career with Pfizer in 1990 and spent nearly 10 years in Pfizer’s Global Research Division in Groton, CT.

In 2000, she transferred to Pfizer’s World Headquarters in New York as a member of the US Commercial Organization, where her primary responsibility was to engage institutions with expertise in pediatric medicine. Here she collaborated on strategic initiatives with foundation representatives, residency program directors, and department chairmen.

In 2002 Ms. Valorie transitioned to Pfizer’s Worldwide Commercial Organization on the Anti-Infectives team and later assumed responsibility for the Xalabrand’s Franchise as the Director of Worldwide Xalabrand’s (Xalatan and Xalacom). In 2009 she assumed full leadership of Pfizer’s glaucoma franchise with responsibilities spanning early development through late stage commercialization of key products. She also leads a cross-functional team which guides research and development efforts in glaucoma. In 2010 she assumed full leadership of the Worldwide Commercial Organization in addition to her current responsibilities, which encompass the areas of glaucoma, retinal disease, and ocular surface disorders.

Ms. Valorie holds a Masters in Business Administration from Rensselaer Polytechnic Institute and a BS in Molecular Biology from the University of Connecticut.

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**Editor:** Gabrielle Bamberger **Designer:** Lisa Grey

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Turning Lunch Hour into Learning Hour

The professional staff at the Johns Hopkins University Applied Physics Laboratory was the most recent group to become better educated about glaucoma through TGF’s Lunch and Learn Program. A member of the Laboratory’s Health Improvement Committee had contacted TGF to schedule a presentation during Glaucoma Awareness Month. On January 20, Dr. Maurice Luntz, a prominent glaucoma specialist and TGF Board member, and Debora K. Grobman, Esq., a TGF Board Member and glaucoma patient, traveled to Laurel, Maryland to present to 130 scientists and engineers. According to the organizer, “the staff gave high ratings to The Glaucoma Foundation.”