TGF’s Cure Glaucoma Now! campaign is steadily moving forward. One year ago, we announced a new focus and goal – the reversal and elimination of exfoliation syndrome (XFS) and its associated glaucoma. Exfoliation syndrome is the most common identifiable cause of open-angle glaucoma in the world, affecting approximately 80 million people, and accounts for the majority of glaucoma in some countries.

Highlighting the past year was the very good news that The Glaucoma Foundation had received a $1.5 million unrestricted gift commitment from The Gerald and Daphna Cramer Family Foundation – the largest single gift in the history of TGF.

The gift enables The Foundation to broaden its research initiatives in a concentrated effort to seek a cure for glaucoma caused by exfoliation syndrome. It was announced at The Glaucoma Foundation’s 20th Annual International Think Tank held in September in New York City and organized by Robert Ritch, MD, Founder of The Glaucoma Foundation and Director of its Scientific Advisory Board, to explore Exfoliation Syndrome: What We Know and Where We Need to Go.

More than 40 participants came from research institutions in the U.S., Canada, Germany, Hungary, Iceland, Ireland, Italy, Japan and Switzerland. TGF’s unique Think Tank, which now focuses on XFS, strives to foster new relationships that will lead to communication and collaboration across disciplines and between laboratories – long after the meeting has ended.

That is happening. Several working groups will continue the conversations begun at the meeting regarding genetics, biomarkers, tissue culture, molecular structure, mechanism of formation of exfoliation material, and new approaches to and methods of treatment.

A Genetics Working Group of attendees has already been formed. In 2007 scientists identified genetic variants in the lysyl oxidase-like 1 (LOXL1) gene that have been strongly associated with XFS, but do not alone cause the condition. The purpose of this working group is to explore research and other opportunities for collaboration on the genetic and environmental risk factors contributing to exfoliation syndrome and exfoliation glaucoma.

About one-third of people with XFS develop elevated intraocular pressure and up to half of these develop glaucoma. With XFS, chances of developing glaucoma are about six times higher than without XFS, and the severity and prognosis of exfoliation glaucoma is worse than that of primary open-angle glaucoma (POAG).
Dear Friends:

2013 was a most important year for The Glaucoma Foundation. It was a year in which TGF embarked on a challenging and exciting journey which we are calling *Cure Glaucoma Now!* Continuing our long held goal of finding a cure for glaucoma, our research and Think Tank focus is now on exfoliation syndrome (XFS), the leading identifiable cause of open-angle glaucoma and the most important cause of complications during routine cataract surgery. You can learn more about XFS on the pages that follow. This is the most ambitious initiative in our history.

We believe a cure for exfoliation syndrome is within our reach and this past year intensified efforts to achieve that goal. As you will read, in September, TGF’s 2013 Think Tank was attended by the vanguard of exploration by medical science into exfoliation syndrome. At this Think Tank we announced The Foundation’s largest gift ever – a $1.5 million dollar commitment from the The Gerald and Daphna Cramer Family Foundation – that enables The Glaucoma Foundation to fund promising projects on a pathway to cure exfoliation syndrome.

Through the *Cure Glaucoma Now!* initiative we are also reaching out and partnering with ophthalmologists who are helping us get the word out and who are encouraging their patients to help underwrite this effort. These initiatives would not be possible without the shared commitment of friends like you who understand that finding a cure now can prevent unnecessary vision loss in our children and grandchildren.

The Glaucoma Foundation extends a sincere “thank you” to the thousands of individuals who contributed to our work in 2013.

Sincerely,

Scott R. Christensen
President and CEO
Exfoliation Syndrome FAQs

How is exfoliation syndrome (XFS) diagnosed?

XFS is a genetically determined age-related disease of elastic tissue within the eye which results in the deposition of a dandruff-like material on the structures in the front of the eye. Diagnosis is made by finding white deposits of this exfoliation material on the anterior (front) surface of the lens and/or pupillary border of the iris. Making the diagnosis often requires a careful slit-lamp examination after dilation of the pupil. In addition to the deposits of exfoliation material, pigment loss from the iris and its deposition on anterior chamber structures of the eye are important signs of XFS.

What are risk factors for exfoliation syndrome?

The prevalence of XFS increases steadily with age in all populations. In the USA, it is much more common in Caucasians than in persons of African ancestry, and women appear more likely to develop XFS than men. XFS has a strong hereditary component. In 2007 scientists identified genetic variants in the lysyl oxidase-like 1 (LOXL1) gene that have been strongly associated with XFS, but do not alone cause the condition. The identification of additional genetic factors that contribute to exfoliation syndrome as well as geographic and environmental factors are goals for future study. XFS is a systemic disease, not just a cause of glaucoma, and is associated with decreased antioxidant capacity and low-grade inflammation in the eye which leads to cataract formation. It has been associated in the literature with an increased incidence of hearing loss, Alzheimer’s disease, and cardiovascular disease.

How is exfoliation glaucoma treated?

Traditional IOP-lowering medications, while less effective in exfoliation glaucoma than in POAG, are used frequently as first-line therapy. Pilocarpine 2%, long regarded as a drug which needed to be taken 4 times a day, can be used once a day at bedtime and this suffices to both increase the rate of fluid outflow through the drain of the eye and also to inhibit the pupil from constricting and dilating in response to external light conditions, thus preventing rubbing of the iris over the lens (the major cause of pigment release from the iris) and reducing the rate of progression of the disease. The next line of therapy often is selective (SLT) or argon laser trabeculoplasty (ALT). Most studies have shown good responses to ALT. But once laser trabeculoplasty starts to wear off, patients with exfoliation glaucoma tend to demonstrate a more rapid IOP increase than POAG patients. This increase is also inhibited if the eye is maintained on 2% pilocarpine after the laser treatment. If medications and laser treatment do not control IOP adequately, traditional surgery, trabeculectomy, may be performed.

What is the prognosis for XFS patients?

With XFS, chances of developing glaucoma are about six times higher than without XFS, and the severity and prognosis of exfoliation glaucoma is worse than that of primary open-angle glaucoma (POAG). At any specific IOP level, eyes with XFS are more likely to have glaucomatous damage than are eyes without XFS. There is greater visual field loss and optic disc damage at the time of detection, poorer response to medications, greater 24-hour IOP fluctuation, more rapid progression and greater need for surgical intervention. The use of pilocarpine to inhibit pupillary movement improves the prognosis. Exfoliation syndrome is strongly associated with cataract formation and is a leading cause of complications during cataract surgery. Early surgery for cataracts is becoming increasingly considered, both to minimize complications and to slow the rate of progression of glaucoma.
Doctor, I Have a Question

QUESTION ANSWERED BY:
Philip P. Chen, MD
Professor and Chief of Ophthalmology,
University of Washington Eye Institute,
Seattle, Washington

What’s the recovery time for laser and trabeculectomy surgery?

Laser surgery is a less invasive procedure than trabeculectomy and has a much shorter recovery time. Laser surgery uses a tiny, powerful light beam to help your eye drain fluid more easily and lower IOP. The procedure takes about 5 to 10 minutes and is usually performed in an eye doctor’s office or outpatient facility. Before the surgery, anesthetic eye drops will be placed in the eye. Following the procedure, the patient may go home and resume normal activities, with instructions to use a topical anti-inflammatory eye drop several times a day for up to a week. Your eye may be a bit irritated and your vision slightly blurry after the surgery, but this will go away in a day or two. Your doctor will likely check your IOP within one or two hours after surgery. Follow up varies among patients, but a typical pattern for exams is one hour, one week and 4 to 8 weeks. It may take a month or more to evaluate if your pressure has decreased to the extent intended. Often you may need to take glaucoma medicines even after your laser surgery. Complications from laser are minimal, which is why this procedure has become increasingly popular, though the success rate is not as high as trabeculectomy.

Trabeculectomy’s goal, like laser surgery, is to reduce IOP, thereby preserving vision. When intraocular pressure cannot be adequately controlled using medications or laser, filtering surgery is often the next step. The operation, in which the doctor creates a new drainage channel, usually is an out-patient procedure, taking from 30 to 60 minutes, and may be longer if your eye has had previous surgery. It is an incisional surgery usually performed under local anesthesia. Several eye drops will be needed until the eye is healed, to help reduce inflammation and decrease the chances of developing a post-operative infection – usually for at least two to three months following surgery. Right after surgery, the patient may experience blurred vision and driving may need to be restricted until the ophthalmologist grants permission. It’s not unusual for a change in glasses to be needed after the eye is well-healed. The number of post-operative visits to the doctor varies depending on patient circumstances, and some activities, such as bending or heavy lifting must be limited for up to several weeks. During the first month after surgery, weekly (and sometimes more frequent) follow-up is often recommended to ensure proper healing. Complications are more frequent and more serious with trabeculectomy than with laser, but IOP control is often better, with many patients no longer using glaucoma medication after surgery. Each case is different, so check with your doctor for specific advice.
LIVING WITH GLAUCOMA

MEET FERNANDO REYES

Fernando Reyes, age 25, says glaucoma has been his push in life. His advice to others: “Don’t limit yourself!” Fernando developed glaucoma at three months and lost sight in his right eye in 5th grade. A native of south Texas, Fernando earned a B.A. degree in history from Southwestern University and an M.A. in Latin American Studies from Tulane University. July marks the end of two years of work with AmeriCorps VISTA in New Orleans, specifically for the Latino Farmers Cooperative of Louisiana – a non-profit network of farmers working to better the life of the Latino community throughout the Greater New Orleans area.

“As a kid all the operations were scary. As an adult, I think more about what it means for my life and future.” Fernando is not able to drive, which makes the logistics of getting round New Orleans a bit difficult. “These logistical problems have never held me back from going the extra mile,” he says. “It’s a matter of stretching boundaries.” I had parents who were very education oriented. And I had wonderful mentors in school, including my debate coach.” Taking his LSAT exam for law school is the next step for Fernando.

“Because of my cultural background and academic interests, it has always been easy for me to drift toward discussions about marginalized Latinos in the United States and participate in work that is aimed at ameliorating the socioeconomic/sociopolitical problems they face.

“However, as much as I am a member of the Latino community, I am also blind and therefore a member of the United States disabled community. And because these are the two communities I identify with, I hope that in the coming years I can become a voice for social justice for both groups as well as an inspiration for the next generation of disabled Latinos.”

MEET THE TILLMANS

April Tillman discovered that her infant son Josh had glaucoma after three pediatricians had missed it. Noticing that his eye was cloudy, she sought help and found his eye pressure (IOP) was in the 50s. That was some 16 years ago – years marked by 15 operations, 4 Ahmed Valves to date, and medications Josh takes throughout the day. In spite of these struggles to maintain his vision, Josh, a high school sophomore in Fayetteville, Georgia, is doing really well. “He’s a great student who thrives socially, and doesn’t let his condition get him down,” says his mother. Josh just celebrated his 16th birthday with his first driver’s license, and is an avid musician, who plays both drums and guitar, and gives drum lessons.

“Too many people slip through the cracks. We almost did and it’s been a scary journey for us. For a long time, we felt so alone, with no one to turn to. But we’ve found support. Groups like TGF’s YUP, which we joined when Josh was much younger, was invaluable to me as a parent. You need to hear other stories – to connect with others. That helps a lot – it’s really been a life raft.”

(Continued on page 9)
Professor Ivan Goldberg
Awarded TGF’s Fifth Annual Robert Ritch Award

Professor Ivan Goldberg, AM, MBBS, FRANZCO, FRACS, of Sydney, Australia, a noted international figure in the glaucoma community, is the 2013 recipient of The Glaucoma Foundation’s Robert Ritch Award for Excellence and Innovation in Glaucoma.

The award recognizes the contributions of individuals who have played a significant and unique role in promoting the medicine and science of glaucoma. It was announced at TGF’s 27th Annual Ball on December 3rd. The award is named in honor of Dr. Robert Ritch, founder of TGF and its Medical Director, who received the inaugural award in 2008.

Prof. Goldberg is Director of Eye Associates in Sydney, head of the Glaucoma Unit and Visiting Ophthalmologist at the Sydney Eye Hospital, as well as a Clinical Associate Professor at the University of Sydney. He is President of Glaucoma Australia and of the Australian and New Zealand Glaucoma Interest Group. In 2009 he was the recipient of an Order of Australia Award “for services to glaucoma and the community nationally and internationally.”

Within Asia and globally, Prof. Goldberg’s experience and knowledge in the field of glaucoma have been recognized through his election as the Founding President of the South East Asia Glaucoma Interest Group (SEAGIG) and later the Asia Pacific Glaucoma Society and President of the World Glaucoma Association (2006-2007). He is also a Past President of the Royal Australian and New Zealand College of Ophthalmologists.

Said Dr. Gregory K. Harmon, Chairman of The Glaucoma Foundation: “We salute Ivan Goldberg’s many accomplishments, including the significant role he has played internationally in the founding and growth of the professional associations that have helped transform knowledge and skills about the diagnosis and management of glaucoma.”
Help Us Find a Cure for Glaucoma

Together, we can find a cure for exfoliation syndrome and hasten the day when blindness from glaucoma is eliminated. The timing is right: TGF is uniquely positioned to succeed. Won’t you partner with us in our campaign to find a cure and make a donation today? Your donations are vital for The Glaucoma Foundation to fund promising and innovative research projects that will bring us closer to our goal. The generosity of longtime and new friends is more important than ever if we are to fund the types of novel projects that TGF has historically encouraged. We urge your renewed support.

Be Social and Find us at –

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New TGF Board Member

John Roberts

John Roberts, a resident of Rye, New York, retired in 1995 from Mobil Oil Corporation, where he was US Lubricants Supply Manager. He currently advises Crowley Chemical Company on oil purchases. Mr. Roberts graduated from Massachusetts Institute of Technology with an advanced degree in Chemical Engineering and later earned an MBA from New York University. Upon graduation, he was commissioned in the U. S. Army and served on active duty as an instructor at the Chemical Corps School. After military service, he joined Mobil as a refinery process engineer and rose through various managerial positions in their U.S. Refining and Supply Departments. Mr. Roberts was originally diagnosed with glaucoma at age 48.

2013 Glaucoma Ball

Art and science were jointly honored at the 2013 Glaucoma Foundation’s Gala Ball, TGF’s primary fundraising event of the year. Held on December 3 in the elegant Manhattan venue called 583 Park Avenue, some 250 guests were on hand for the presentation of the Kitty Carlisle Hart Award of Merit for Lifetime Achievement to noted sculptor Strong-Cuevas. The 2013 Robert Ritch Award for Excellence and Innovation in Glaucoma was presented to Professor Ivan Goldberg of Sydney, Australia, a highly regarded member of the international glaucoma community.

Left: Honorees Strong-Cuevas and Prof. Ivan Goldberg.
Right: Barbara Hearst, Dinner Chair, and Scott Christensen, TGF President and CEO.
CURE GLAUCOMA NOW! GAINS MOMENTUM

(Continued from Cover)

In addition to potential blindness from glaucoma, exfoliation syndrome is a leading cause of complications during cataract surgery. A growing list of associations with cardiovascular and cerebrovascular diseases such as stroke, cardiovascular dysfunction, Alzheimer’s disease and hearing loss makes XFS a condition of significant medical importance.

In spite of these compelling facts, little attention was paid to exfoliation syndrome until the beginning of the 21st century. The recent identification of the gene defect associated with this disorder has helped accelerate research. Scientific advances in our understanding of proteins, chemistry, and the function of the eye have come together at this moment to provide a unique opportunity.

With the impetus of The Glaucoma Foundation and its annual Think Tank, interest is growing. The Glaucoma Foundation is committed to finding a cure for exfoliation syndrome and hastening the day when blindness from glaucoma is eliminated.

LIVING WITH GLAUCOMA

(Continued from 5)

April suggests one has to be one’s own self-advocate – especially where emotional support is concerned. Josh, too, has learned to advocate for himself – in terms of communicating with his teachers about what he can and cannot do. But Mom April has learned not to rule things out. During a New Year’s trip in the mountains Josh learned he had a talent for skeet shooting.

Josh had to have surgery again in September after being stable for 5 years. “All’s well right now,” April Tillman reports. “We don’t know what’s in store for Josh down the road, but we are hopeful that glaucoma will not define him and that one day there will be a cure!”
begun at the meeting regarding genetics, to and methods of treatment. Groups will continue the conversations about the genetics of exfoliation syndrome (XFS), a leading cause of primary open-angle glaucoma (POAG). XFS, chances of developing glaucoma are about six times higher than without XFS. About one-third of people with XFS develop elevated intraocular pressure and up to half of these develop glaucoma. With exfoliation glaucoma is worse than that of primary open-angle glaucoma (POAG).

Exfoliation syndrome is the growing list of associations with cardiovascular dysfunction, Alzheimer's disease and hearing loss makes XFS a condition of significant medical importance. In spite of these compelling facts, little attention was paid to exfoliation syndrome until the year ago, when the impetus of The Glaucoma Foundation and its annual Think Tank, interest is growing. The Glaucoma Foundation is committed to hastening the day when blindness from glaucoma is eliminated.

The Gains Momentum

We know and where we need to go. With the impetus of The Glaucoma Foundation and its annual Think Tank, interest is growing. TGF's unique Think Tank, which now focuses on XFS, strives to foster new relationships that will lead to opportunities for collaboration on the structure, mechanism of formation of the lysyl oxidase-like 1 (LOXL1) gene and exfoliation glaucoma. Several working groups will continue the conversations about the genetics of exfoliation syndrome (XFS), a leading cause of primary open-angle glaucoma (POAG). XFS, chances of developing glaucoma are about six times higher than without XFS. About one-third of people with XFS develop elevated intraocular pressure and up to half of these develop glaucoma. With exfoliation glaucoma is worse than that of primary open-angle glaucoma (POAG).

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