THE GLAUCOMA FOUNDATION NEWSLETTER

January 2021

Glaucoma Awareness Month

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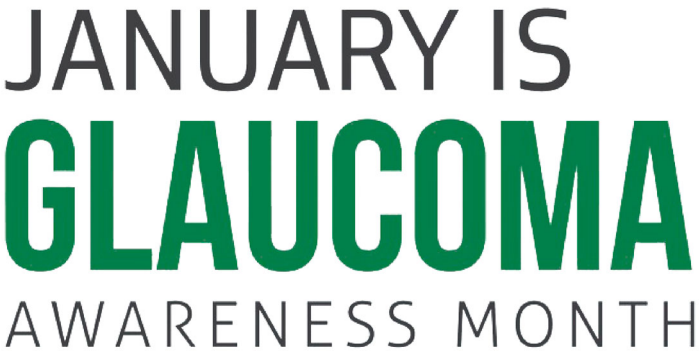


BE WELL-INFORMED

Here's a New Year's resolution that can save your sight: make that call to schedule an appointment to have your eyes tested. The pandemic forced many offices to close in early spring but many reopened in the summer, even if seeing fewer patients than before the pandemic. While COVID 19 is still rampant in some areas, doctors have put protocols in place to safely see patients who require care.

Early detection and continuing treatment are key to preserving your vision. Sifting glaucoma facts from fiction is also crucial. Here are some common misconceptions.

Myth: There are warning signs for glaucoma.

With open-angle glaucoma, the most common form, there are virtually no signs or symptoms. Contrary to popular thinking, pain is not associated with increased eye pressure. What's more, vision loss usually begins with peripheral, or side vision, so you may not be able to tell right away that your vision is impaired. The only way to tell if you have glaucoma is to have an eye exam with an eye care professional who tests for glaucoma.

Myth: Glaucoma only affects the elderly.

Glaucoma can affect people of all ages. The risk of glaucoma increases as we get older and the majority of a specific type of glaucoma called open-angle glaucoma is age-related. However, glaucoma can affect people of all ages, even newborns. For example, some babies have congenital glaucoma, while other children have eye diseases that lead to secondary glaucoma.

Myth: All people with glaucoma have elevated intraocular pressure (IOP).

Elevated IOP is a risk factor for glaucoma and is not the disease itself. There are many different types of glaucoma, and not all of them are associated with elevated IOP. The common thread among all glaucomas is damage to the optic nerve rather than elevated IOP.

Myth: Glaucoma is curable.

Glaucoma is a chronic condition that needs ongoing treatment and monitoring. If damage has occurred, at this time it is irreversible. Early detection and treatment minimize the risk of permanent vision loss.

Message From the President

Dear Readers,

As we ring in 2021, we want to thank each of you who helped us to keep our momentum over these past, often difficult, months. We hope that you are safe and well. While we expect that life will remain in flux for some time, we are confident that the new year will bring further, meaningful advancements in glaucoma research and treatment.

The Foundation has just entered into a significant new partnership with **Research to Prevent Blindness** (RPB), a major funder to 35 leading scientific institutions in the U.S. working on a diverse range of disease-oriented research. Together, we will be co-funding five new $10,000 supplemental fellowships targeted to under-represented minorities, as defined by the NIH, who are fellows in Departments of Ophthalmology engaged in substantive glaucoma research. TGF fellowships were first founded in 2020 by board member Patricia Hill as the Patricia Hill-Dr. Sanford Eisenberg Fellowships in Glaucoma. We are honored that RPB is joining us in support of these young doctors.

Our two organizations will also jointly grant an annual $150,000 **TGF/RPB Advancement Award in Glaucoma Research** to assist early-career ophthalmic scientists in pursuit of ongoing research of unusual significance and promise. This award will focus on the degeneration of human retinal ganglion cells with openness to connectomic, genetic, imaging, epidemiologic, and regeneration approaches. It will be available to assistant professors who have already received their first NIH R01 grant, a group identified by RPB's Scientific Advisory Panel as representing a critical gap in the funding pipeline. Funding here will be important both for the field of vision research at large and for advancing the research and careers of individual vision scientists.

In November, **Dr. Deborah Wallace** and her team at University College in Dublin published their research on pseudoexfoliation glaucoma, the most common cause of secondary open-angle glaucoma worldwide. Dr. Wallace's work was funded in part by a 2015 grant from TGF. The article references the contributions of many other TGF-affiliated scientists who have been engaged with us on this subject over the past decade.

Dr. Simon John of Columbia University, a former member of our Scientific Advisory Board

and for many years an active participant in our Scientific Think Tank, is a world-renowned glaucoma researcher. He was honored last month with the prestigious **Sanford and Susan Greenberg Visionary Prize to End Blindness.** The award will support him and his team as they focus on diseases that damage the retinal cells connecting the eye to the brain and develop approaches to regrow their connections.

On Saturday morning, February 27, TGF will host **"Bringing the Latest Glaucoma Science Directly to the Patient,"** an online conference and Q&A with glaucoma patients and four leading experts. Please join us for discussions on the importance of trust between patient and physician; possibilities in optic nerve regeneration; novel procedures and surgeries; and the role of artificial intelligence in glaucoma diagnosis and treatment.

Register here to join us and ZOOM will send you a reminder email when it's time to log in.
https://zoom.us/webinar/register/8116097821476/WN_yBG_xL45Q4K98lJfPQRlug

In closing, we want to thank you for being a TGF newsletter reader. We look forward to continuing our series of interviews with TGF Founder Robert Ritch and hope to answer questions and address subjects of importance to you. If there are topics you would like us to explore in upcoming issues, please write to us at info@glaucomafoundation.org.

With best wishes for a happy, healthy year to come,

Elena Sturman
President & CEO

Advancing Our Knowledge Over The Decades
Forty Years of Extraordinary Achievement

This summer, Dr. Robert Ritch retired from clinical practice and academic positions at the New York Eye & Ear Infirmary of Mount Sinai because of health issues. His remarkable career has been devoted to broadening our understanding of the underlying etiologies and mechanisms of glaucoma and innovations in its treatment. He has treated thousands of patients who credit him with saving their vision.

This interview was edited from a recent conversation between Dr. Ritch and the Foundation's president and CEO, Elena Sturman. It will be the first in a series.

E.S. Bob, it's such a pleasure to talk with you today. You have been one of the most brilliant minds in glaucoma for more than forty years. What do you consider to be the greatest achievement of your career?

R.R. That is difficult to answer because I can think of a number of important milestones over my lifetime, beginning with an epiphany one evening when I first found out what glaucoma is.

I started medical school in 1968 and my residency in ophthalmology in 1973, specifically because I wanted to cure glaucoma. I finished a double fellowship in 1978. At that time, 90% of glaucomas were not even diagnosed. Glaucoma was still equated with high intraocular pressure (IOP) and population studies in the 1950s had shown the average IOP in populations to be about 15.5 millimeters of mercury (mmHg).

The pundits of that time took two standard deviations from the mean to be abnormal so that the range of "normal" IOP was thought to be about 9 to 21. By this definition, 22 was defined to be glaucoma, and everyone with 22 mmHg or greater IOP was treated.

There were only three classes of medications, and all had discomforting or even dangerous side effects. There were no lasers and the only option if medication did not work was surgery.

Two important concepts had been developed in the 1960s. The first of these was that not everyone with IOP 22 or more had glaucoma when glaucoma was defined by the presence of visual field loss. Those without glaucoma damage were termed ocular hypertensives, a category now often included as glaucoma suspects. The second major concept was the cup-to-disc ratio (C/D ratio). This is the diameter of the optic cup, the pale center of the optic disc through which contains the retinal arteries and veins. A C/D ratio of 0.1 to 0.3 was considered normal, and greater than that either suspicious or glaucomatous. Patients with normal C/D ratios and no visual field damage were taken off medications and, as the pendulum swung from one direction to the other, patients with IOPs as high as 40 mmHg or more were followed without medications until they developed visual field loss.

We now know the truth lies somewhere in between. I came up with the term OPCOP (ophthalmologist's psychological cut-off point) at which the ophthalmologist felt obliged to treat in the absence of glaucomatous damage (mine was 30 mmHg).

This is where things stood in 1979 when I attended a symposium of the National Society to Prevent Blindness. They had done a survey of 1001 adults across the country and found that 30% had never heard of glaucoma, 50% had heard of it but didn't know what it was, and 30% "knew" that glaucoma was associated with elevated IOP but 75% of those thought that it was easily detected, easily treated, and rarely caused blindness. Only 5% of the population had an accurate idea about glaucoma as it was defined at the time.

It was a vastly different world when I began...Almost always, the diagnosis was missed.

I was really shocked by the lack of awareness about glaucoma, not only by the population at large but by physicians. (There were only about 30 ophthalmologists in the U.S. known as glaucomatologists at the time – now there are 1400.) Several ophthalmologists asked me why I wanted to specialize in glaucoma, and one said, "There is not enough glaucoma to make a practice from it." I saw it very differently. It was all over the place.

Normal-tension glaucoma, defined as a highest untreated IOP of 21 mmHg or less was regarded as rare, and even many glaucoma specialists did not believe in it. In fact, it accounts for 30% of glaucoma in the U.S. and as much as 90% in Japan. Almost always, the diagnosis was missed. Other glaucomas, termed secondary glaucomas, were identified by specific findings on slit-lamp examination but they were not recognized as specific disorders apart from primary open-angle glaucoma, and all were treated the same way. Angle-closure glaucoma was believed to be primarily a disease in East Asia and uncommon in the U.S.

In 1983, another epiphany. I saw a flyer in an elevator for a colostomy patient discussion group and my mind immediately flashed to glaucoma. I started a glaucoma patient group – I believe the first in the world. Today it has 400 members. In 1985, with about 10 patients as supporters and board members, I created The Glaucoma Foundation. The Glaucoma Research Foundation, started by Drs. Shaffer, Hetherington, and Hoskins, was formed independently at the same time.

E.S. You did something unique and revolutionary when you engaged scientists from other disciplines in the study of glaucoma.

R.R. Yes, in 1994, the Foundation launched the annual Optic Nerve Rescue and Regeneration Think Tank. The concept of neuroprotection for glaucoma came out of our first meeting. Over the years, we moved on to molecular genetics, animal models,

nanotechnology, gene therapy, stem cells, tissue bioengineering, and other topics. We always had two goals in mind: to hold a meeting on a topic that had never been done before in association with glaucoma and to try to bring different fields together to create a new one. We have limited the meeting to 40 participants, only some of whom are glaucoma specialists and who are outnumbered by the PhDs. We invite people who are leaders in their fields but may not know anything about glaucoma until they come to the Think Tank. We want to know how their fields can apply to glaucoma. Many of the new attendees become interested in glaucoma research and many have gone on to become leaders in the field, winning research grants and awards for their work.

Scientific Think Tank, NYC 2019

One of my favorite things throughout my career has been to overthrow theories that have been regarded as gospel for half a century. For instance, patients under age 35 rarely if ever had their IOP checked because patients under age 35 were not supposed to get glaucoma. I was asked about this once on TV and I said “Yeah, but I have 3000 on my database.” Pigmentary glaucoma was thought to be rare but was not – it was just vastly underdiagnosed because it affected people in their early 20’s; the diagnosis was often missed until they lost sight in one eye. I saw many infants and children with congenital glaucoma and various syndromes, and I started the first pediatric glaucoma clinic in New York.

In 1995, I started **alt.support.glaucoma** as an internet discussion group. Ivan Goldberg in Australia and I co-chaired the first World Glaucoma Day as part of the World Glaucoma Association. This was an enormous task for two people as we had to contact every

national and international glaucoma society. It grew rapidly; World Glaucoma Day became World Glaucoma Week with a large program held annually in March in many countries.

Today we have The Glaucoma Foundation, the Glaucoma Research Foundation, the World Glaucoma Association, and World Glaucoma Week, all of which are large and prominent, and have done a great deal toward raising public consciousness, conducting conferences, providing grant support, and creating publications for patients.

It was a vastly different world when I began. So, although I find it hard to pick out a single discovery, or finding, or surgical development as my greatest achievement, I think that raising glaucoma awareness is one of the most important things I have done. I went on TV to talk about glaucoma, I wrote articles about glaucoma, and then I got into dividing glaucoma into subcategories because everybody was looking at glaucoma as a single disease that began with an IOP of 22. The Glaucoma Foundation has taken the lead in bringing exfoliation syndrome to the world's attention. It used to be thought of as a disorder peculiar to Scandinavia, but it has since been shown to be present world-wide and to affect about 60 million people. The goal of the Think Tank for the past several years has supported the idea that this is a potentially preventable and reversible disease.

Many new developments are happening very rapidly with the advent of new techniques and discoveries. These include artificial intelligence, big data, deep sequencing, gene therapy, and more.

Glaucoma may be treated by lowering IOP, and lowering IOP has been the only treatment proven to slow the progression of glaucoma. But I think many new areas of inquiry and discovery lie ahead. Glaucoma affects the optic nerve, which is part of the brain, so glaucoma is really a brain disease. But we have not proven that agents that slow neural diseases slow glaucoma progression – yet. It is coming. And the diseases that cause high IOP affect the optic nerve and thus we can look at the end result of all these disorders that lead to glaucoma as a brain disease.

In our next installment, I'd like to discuss so-called secondary glaucomas - which are actually specific diseases of the eye that cause glaucoma - such as exfoliation syndrome and pigmentary glaucoma. Also angle-closure glaucoma, and normal-tension glaucoma which has become so important today.

E.S. Thank you, Bob, for this fascinating overview of the evolution of glaucoma awareness and knowledge and your important role in the progress we've seen to date. We look forward to future articles in this series.

Nearly all treatments, including drugs and medical devices, require clinical trials and approval by the government's Food and Drug Administration (FDA). The journey from a scientific breakthrough to a treatment you can access is a long one -- taking years. (The recent approvals of COVID-19 vaccines are welcome exceptions to that timeframe.)

A clinical trial is a research study using human volunteers, referred to as participants, to answer specific health questions. In general, clinical studies are designed to add to medical knowledge related to the treatment, diagnosis, and prevention of diseases or conditions. These studies are conducted to evaluate whether the new treatment, procedure, or device is safe and effective. Clinical trials can be sponsored by the government, by academic institutions, and by industry, and usually involve at least three phases.

Phase 1 clinical trials evaluate the safety and dosage of a drug or treatment to determine how well it works. This testing normally takes place with a small group of healthy volunteers. If the trial meets the primary outcomes, as proposed in the application to the FDA, then the FDA permits the trial to proceed to Phase 2.

Phase 2 clinical trials test the efficacy and side effects in treating a particular disease, with several hundred participants with the disease.

Phase 3 clinical trials are the ultimate test of whether a treatment is safe and effective for a wide variety of people, and typically involve a much larger group of volunteers for a longer period of time than Phase 1 and 2 trials. Just like Phase 2 trials, the plan normally involves assigning participants to treatment or control groups.

Choosing to participate in a clinical trial is an important personal decision. If you or someone you know is interested in learning more, it is important to talk to your doctor and family members. All clinical trials have guidelines about who can participate. Each has its own protocol or set of guidelines, and volunteers must meet certain criteria to qualify for inclusion. Because small groups and select doctors are involved with trials, don't expect your doctor to have specific details on each study. Be sure to understand that expressing trial interest does not guarantee involvement nor does it guarantee that you will be

included in the treatment group. If you want to learn more, try these resources:

www.clinicaltrials.gov
An easy-to-use website that provides regularly updated information about federally and privately supported clinical trials. You can find specific clinical trials for a wide range of diseases.

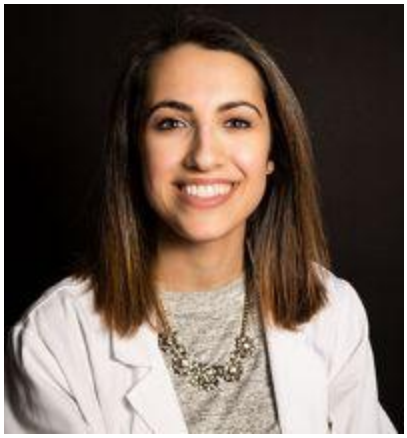
Glaucoma-related trials globally are accessible in one section – with such details as location, sponsor, and status (completed, active, recruiting, etc.).

www.CenterWatch.com
Offers a clinical trial database with currently enrolling trials, information on the trials process, and on drugs and new medical therapies.

www.researchmatch.org
A free and secure registry that brings together people who are trying to find research studies and researchers who are looking for people to participate in their studies.

https://www.nih.gov/health-information/nih-clinical-research-trials-you/basics
This NIH Clinical Trials and You website is a resource for people who want to learn more about clinical trials.

The Benefits of Low Vision Therapy



Delaram Shirazian, OD

On December 9, The Glaucoma Foundation held a webinar featuring Delaram Shirazian, OD, who presented “An Overview of Low Vision Rehabilitation.” Dr. Shirazian is an

Assistant Clinical Professor at SUNY College of Optometry who works with patients and students in primary care and low vision rehabilitation clinics.

Low vision is often defined as a condition in which visual acuity is 20/70 or poorer in the better-seeing eye and cannot be corrected or improved with regular eyeglasses.

But a primary takeaway from Dr. Shirazian's presentation was that low vision rehabilitation does not require a specific level of vision loss. The purpose of low vision therapy is to maximize the vision you have remaining.

Legal blindness is another category of vision loss – one used by the U.S. government to determine who may be eligible for certain state benefits. It is defined as visual acuity of 20/200 or less in the better or stronger eye with best correction, or, as a restricted field of vision of 20 degrees or less in the better or stronger eye.

While eligibility for some state services may require a patient to be legally blind, Dr. Shirazian stressed that when low vision begins to interfere with daily activities, that's the time to have a low vision exam.

"I may see a patient who has 20/20 vision but has enormous sensitivity to light or glare, and needs help with determining what tint is best for glare control," she says. "Or, someone who needs to read small print, or does needlework, and may be struggling with acuity loss."

A low vision exam is different from a regular eye exam for glaucoma, which focuses on making sure your disease is well-controlled. "We want to know how you are functioning with the vision that you have – it's a goal-based exam," she says.

The exam looks carefully at the patient's medical and ocular history, and at how the patient deals with activities of daily living – can you read your mail, cook without burning yourself, take public transportation? It also measures different facets of acuity -- with charts for contrast sensitivity, various distances, etc., as well as visual fields. The goal is determining the best prescription for your needs.

Low vision individuals may be at increased risk for depression and anxiety and these stresses are also assessed during a low vision examination. Referrals are made to mental health resources. In New York, the Lighthouse Guild has mental health providers who work with patients with vision loss. Support groups are also really important and beneficial.

Beyond eyeglasses, there are many devices available today to help meet a patient's needs. Dr. Sherazian noted the availability of built-in magnifiers on IOS smartphones that can change contrast and font size, VoiceOver – a built-in screen reader on iPhones, and

Seeing AI -- a free iPhone app that uses artificial intelligence that enables reading text out loud!

Devices range from hand-held and standing magnifiers with adjustable magnification and contrast levels for prolonged reading to the hands-free Optivisor headband magnifier, glasses with a telescope attached, and hand-held monoculars for spot reading and spot tasks.

While Medicare typically will pay for a low vision exam by an eye doctor, it does not reimburse for low vision devices. And some hi-tech devices come at a high cost. For instance, there's new wearable technology like the Orcam device that utilizes a scanner on the side of your eyeglasses to read text out loud to the wearer. At the market, it could scan product labels.

How does one find a low vision specialist? The first step is to ask your regular eye doctor. In New York State low vision specialists are certified and there is a website that lists providers – **www.primarycareopt.com.**

More information at: **Patient Resource Center – The Glaucoma Foundation**

Dr. Shirazian's webinar can be accessed in full on the TGF website at **Events – The Glaucoma Foundation**

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thank you for giving