



# SEARCHLIGHT ON GLAUCOMA

The Glaucoma Service Foundation to Prevent Blindness

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## Letter from the President



For the past three years, I have served as a Trustee of the Glaucoma Service Foundation. This June, I was honored to be elect-

ed as Foundation President. I assumed the position confident that with the strong support of our Trustees, Foundation committee members, and Glaucoma Service physicians, that we will continue to make a difference in the fight to eradicate glaucoma, the second leading cause of preventable blindness.

In Philadelphia, our African American, Hispanic, and Asian American populations, as well as individuals over sixty years of age, are at the greatest risk for glaucoma. As a Foundation, we are committed to supporting out-

reach initiatives that increase awareness about glaucoma within these high-risk populations. Indeed, with early diagnosis and proper treatment, many glaucoma patients are able to preserve their sight and live normal lives.

This year, the foundation's annual Cares Conference brought 270 attendees to the Jefferson University campus in April for information about the latest glaucoma treatment options, the opportunity for interaction with Glaucoma Service physicians, and the sharing of concerns with other glaucoma patients and caregivers. A highlight of the day-long event was the attendance of some eighty members of the Chinese Coffee Cup Senior Center who received a special presentation about glaucoma in Mandarin as well as the opportunity for on-site glaucoma screening and if needed, referral to

Wills Eye Hospital. Our outreach initiative was well-received and we look forward to reporting about similar activities for other high-risk populations in the Greater Philadelphia area.

Support for programs such as the Cares Conference and our recent wine tasting event highlighted by our inspirational speaker, Amy Dixon, requires financial support from the Foundation's "friends" as does support for the research of our Glaucoma Service physicians and the Fellows who are training to become the glaucoma specialists of the future. Simply put, your generosity can help us move closer to the goal of a "blindness-free" Philadelphia. I hope you will help us do so.

Sincerely,  
Maxine Colm, President  
Glaucoma Service Foundation



## Glaucoma Service Foundation's 7th Annual CARES Conference

The 7th Annual Glaucoma Service Foundation's CARES Conference was held on April 26, 2014. This year we changed our venue to Jefferson Hospital, Dorrance Hamilton Building, located at 1001 Locust Street, Philadelphia, PA. In addition to lectures by world-renowned Wills Eye glaucoma physicians, attendees had the opportunity to speak with those physicians. Guest speakers included Dennis Steiner (Vision Corps), Brittany Morgan (Chat Room volunteer), Diane Brown (Philadelphia Corporation for Aging), and Joe Saunders (Center for the Blind and Visually Impaired). "Ben Franklin" also made an appearance and had his vision checked. This year we had approximately 270 attendees. Free glaucoma screenings were available throughout the day. Alice Zhang, a Jefferson medical stu-



**Tim Sullivan, Glaucoma Clinical Fellow performs screening on CARES attendee**

Photo: Robert Kump

dent, gave a special power point presentation in the lobby, to the Chinese Coffee Cup Senior Center. There were two people that were diagnosed with glaucoma who did not know they had the disease.

The Foundation is extremely grateful for the many volunteers who made this event possible:

Glaucoma Service staff members and their families, clinical and research fellows and observers, Wills Eye and Jefferson residents and medical students, members of the Foundation's Board of Trustees, Villanova's Delta Gamma Sorority, and Bill Romano for overseeing the audio/visual tasks.

The Robison D. Harley Fund for Glaucoma Education and Research sponsored this event. The following generously provided gifts-in-kind: Allergan, Carl Zeiss Meditec, DeVitis Design, Philly Soft Pretzel, Associated Services for the Blind, and the Wills Eye Glaucoma Research Center. Save the date for our 8th Annual CARES Conference scheduled April 25 2015. We hope to see you there. CARES registration and information can be found at [www.willsglaucoma.org](http://www.willsglaucoma.org) ■

## ORCAM: Promise for Liberating Patients with Glaucoma

Leonard Rosenfeld, Vice President

I am a retired medical educator, having spent my entire professional career on the faculty of the Jefferson Medical College in Philadelphia. I taught physiology to medical students, graduate students, nurses and physical therapists. I conducted medical research on the functions of the gastrointestinal tract. My last eight years I served in an administrative

capacity as Assistant Dean of Jefferson's College of Graduate studies.

In 1981, I was diagnosed with glaucoma. I felt that my career was in jeopardy and the future quality of my life in question. Fortunately, expert care from George L. Spaeth, MD at Wills Eye Hospital allowed me to maintain a full career which included Presidency

of the Pennsylvania Academy of Science, Chairmanship of the prestigious Committee on Science and the Arts at the Franklin Institute and, Presidency of my local Board of Public Education.

Despite superb medical care at Wills, my vision has deteriorated over the years. For example, in the ten years since my retirement, I

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## ORCAM: Promise for Liberating Patients with Glaucoma

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have been unable to read my mail unassisted. This summer, I was offered a unique opportunity by L. Jay Katz, MD, current Director of the Glaucoma Service at Wills Eye, to participate in an evaluative study of an exciting new device. ORCAM is being developed by the ORCAM Corporation of Jerusalem, Israel. The Glaucoma Service of Wills Eye Hospital has been selected to perform the first external evaluation of this device, and I am pleased to be among the first patients given the opportunity to use it. An ultra lightweight camera is affixed to the side arm of a pair of eyeglasses, connected by cable to a small computer unit which is no larger than a pack of cigarettes. A "photograph" is taken of a page of text and the computer has the capability of "reading" the text and translating it into words which the user can hear. It is hard to express the excitement that such liberation evokes; I am "reading" letters, professional reports and other material for the first time in years! The device is not perfect but that is the reason for conducting an evaluative study... to identify problems or shortcomings and to allow ORCAM's professional staff to further refine the device prior to its release to the general public. After using the device for several weeks, I could not be more positive in my personal evaluation. ■

## Being an Empowered Patient

Amy Dixon CSW and Glaucoma Patient

I am a very lucky patient. One might not say that given I've had 16 eye surgeries in less than 5 years, countless in-office injections and procedures, and nearly two years of chemotherapy to treat my rare eye disease. But I am lucky. I have these as options, while many do not. I have a 5 year background as a student working towards her doctorate in pharmaceuticals at the University of Connecticut. I lived, ate, and breathed the chemistry world for 5 years of my life. Never would I have imagined how important a role that would play in my own care and disease. I also happen to live in the Northeastern United States, home to 3 of the top Uveitis (Inflammatory Eye Disease) Specialists in the world, AND the world's most renowned Glaucoma specialist, less than a 45 minute drive away. Lucky? You BET I am!

You don't HAVE to have a PharmD or PhD to know how to advocate for yourself when dealing with a serious illness, however you just have to be your own inner, pushy self. That person that you hide from the world who sits inside of you and is constantly asking, "What now? What IF? How do I do \_\_\_? Is this drug better? Will it make me sick? What is the next step if this doesn't work? What are the statistics on this treatment? At what stage is my disease? Are there other people nearby who have this? How can I talk to them?" You NEED to address all of those nagging questions in your head. Being a shy, fearful, victimized patient serves NO

ONE well. In fact, you are doing yourself harm each time you don't ASK a question.

Doctors are incredibly busy. Often you'll get to your appointment on time to see a specialist and be 'graced' with their presence' after a nearly 90 minute wait. Under NO circumstances should you feel RUSHED. Make a list of questions in advance, and be sure to ask alternatives / options to the treatment they are suggesting and WHY, side effects, next steps, and how YOU personally can improve the outcome through either exercise or diet or rest, whichever they recommend most.

Going to a specialist can be intimidating. Sitting across from an 'expert' about your disease is frightening. It can feel like they have all the cards in their hand, but in FACT, it is quite the opposite. Their reputation is based on how successful they are at treating people just like you and me. If they aren't successful in managing or defeating your disease, it is a personal loss for them. It is YOUR job to 'challenge them' to step their game up on your behalf. Every decision is ultimately yours, no matter HOW 'matter of fact' they sound or determined to pursue a certain course of treatment; it is your JOB to question the WHY at each and every turn. Make them accountable, and don't be afraid to interject a little PERSONAL information about yourself.

Because of the rarity of my disease, I

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## Being an Empowered Patient

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am still able to see out of 1% of my eye, and that is no miracle. That was the hard work of the world's best working on my behalf and pulling out every strange and rare surgery and implant and medication.

When you are faced with a difficult diagnosis, Google can be both your best friend and worst enemy. Balancing the dizzying array of info on the internet and the advice of your doctor can be a full time job. Make it so. But also remember that the internet reports the WORST case scenario of each and every drug and treatment for liability purposes. You will not necessarily fall into that category. However, DO take note of something amiss or odd during your treatment, even if it's seemingly insignificant, or doesn't 'fit' with the known side effects. The

first chemo drug I was given was supposed to have MINIMAL side effects, and would be very well tolerated by most patients. I was unable to walk due to severe vertigo after taking my very first dose. This was a side effect that had NOT been reported to the FDA and my doctors were baffled for 6 weeks until they finally took me off of it and I was able to finally stand up.

Remember that everyone responds differently to treatments and medications and that no two patients or outcomes are alike. I belong to 4 different eye disease support groups for my various conditions, and have to remember that in every country the protocols and drugs are different and that each of us heals differently also. Just because my friend Lisa had a disastrous trabeculectomy, doesn't mean that I too am going to be affected the same way. But DO take note of these other outcomes to PREPARE

yourself for this possibility. Find a support group that is focused on treatments and sharing outcomes. Being part of a group will make your disease less isolating, and you may find treatments, doctors, and drugs that you hadn't known about otherwise. Support groups can be useful tools in healing both physically and mentally. However, DO remember, that these folks are PATIENTS just like you, and to take their opinions with a grain of salt. They're looking for answers just like you.

So I want you to march into that doctor's office next time, whether it's for you, your spouse, your child, or your parent, and OWN IT. The doctors work for YOU. You are PAYING them for a service. You are NOT a bother. You are their life's ambition and work. Become an expert patient. You will NEVER feel helpless again. ■

## Wills Eye Hospital: 5-year CDC-Funded Project: October 1, 2014 to September 30, 2019

### Wills Eye Community Intervention to Improve Glaucoma Detection and Follow-up Care

Under the leadership of L. Jay Katz, MD; Julia A. Haller, MD; and Lisa Hark, PhD, RD, the Wills Eye Glaucoma Research Center has been awarded a 5-year, \$1.3 million cooperative agreement from the Centers for Disease Control and Prevention. The study aims to conduct a prospective, randomized, controlled trial to test an innovative community intervention using fundus photography of the optic nerve and macula (telemedicine) to detect, treat, and manage high-risk patients

with previously undiagnosed glaucoma and other eye diseases. Our diverse, targeted at-risk population includes African Americans, Hispanics, and Asians over age 40; older adults (aged 65+); and those over age 40 with a family history of glaucoma and/or diabetes.

#### Phase 1

Phase 1 will consist of recruiting approximately 2,000 patients from 14 primary care offices and 10 federally qualified health centers across

Philadelphia and Chester counties with our community partners. We will detect eye disease using telemedicine (Visit 1) followed by a comprehensive eye exam by a glaucoma specialist to confirm the diagnosis (Visit 2). Based on preliminary data, 30% of patients (approximately 600) will have abnormal optic nerve and/or macula images. Using results from the comprehensive eye exam, we will determine

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## Wills Eye Hospital: 5-year CDC-Funded Project:

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how accurate the optic nerve images are in detecting patients with glaucoma and glaucoma suspect.

### Phase 2

Phase 2 will involve consenting, enrolling, and randomizing 300 patients to either the usual care group (n=150) or the enhanced intervention group (n=150) and scheduling follow-up eye exams with local, general ophthalmologists (Visit 3).

The enhanced intervention will consist of using patient navigators and a social worker to reduce barriers to follow-up eye care.

### Phase 3

Phase 3 will consist of following patients proximally (6 months) and distally (3 years) while they attend ophthalmology appointments (Visits 4-8). Adherence to follow-up recommendations for eye care will be the primary outcome measure. A comprehensive cost study to estimate the intervention costs and cost-effectiveness of detecting eye

diseases and vision impairment in a high-risk population will also be conducted. Protocols, materials, and results will be disseminated to other communities in order to expand detection of glaucoma, other eye diseases, and visual impairment, and to further refine these approaches. ■

Contact:

Lisa Hark, PhD, RD  
Director, Glaucoma Research Center  
Wills Eye Hospital  
Professor of Ophthalmology  
Jefferson Medical College

## Glaucoma Service Foundation Announces Dr. Sarah Kuchar 2014-2015 Foundation Fellow



At its June meeting, the Board of Trustees of the Glaucoma Service Foundation

selected Sarah D. Kuchar, MD, as the 2014-2015 Foundation Fellow. Dr. Kuchar's training on the Glaucoma Service at Wills Eye Hospital between July 2014 and July 2015 will be sponsored by the Foundation thanks to support from readers like you. Dr. Kuchar, a New Jersey native, trained as a Resident at Wills Eye Hospital from 2011-2014, serving as Co-Chief Resident for 2013-2014. She holds degrees from Robert Wood Johnson Medical School and Yale University.

Fellows sponsored by the

Glaucoma Service Foundation take part in clinical and surgical training for the care of glaucoma patients alongside the Wills physicians. In addition, they participate in clinical research studies, with their work often appearing in medical journals and presented at national ophthalmic conferences. For more than three decades the Glaucoma Service Foundation has been proud to support such training.

### Glaucoma Service Foundation to Visit Vine Memorial Baptist Church

On October 25, 2014 the Glaucoma Service Foundation will visit Vine Memorial Baptist Church in West Philadelphia. Thanks to a generous grant from the Thomas Skelton Harrison Foundation, we will be hosting a lecture on glaucoma: its

prevalence, symptoms, and resources available to those diagnosed. African Americans are at a higher risk of glaucoma, and they are more likely to have an aggressive disease. Vine Memorial, an African American congregation, will give the GSF an opportunity to share this message with individuals at heightened risk for glaucoma. We hope that this will be only the first of many such lectures in the future.

Vine Memorial Baptist Church is located at 56th Street and Girard Ave in West Philadelphia, founded in 1932. Rev. James S. Allen, Sr. has served as Pastor of the congregation since 1978, only the second Pastor in their more than 80 years. ■



# Second Annual Wine Tasting Fundraiser

Katerina Simonetti, CFP and Trustee

On Saturday, September 6th we had our Second Annual Wine Tasting fundraiser at the Gulph Mills Golf Club and it was a smashing success!!

In addition to exceeding our fundraising goal, we had a great time socializing with many of our guests, including patients, doctors and board members.

Here is a short recap of the evening for those of you who were not able to join us:

- 85 guests enjoyed the evening
- Dr. George Spaeth talked about glaucoma and emphasized the fact that it is still the second leading cause of preventable blindness
- Dr. Jay Katz gave an update on the latest advancements in glaucoma treatments



(left to right) Amy Dixon, (Speaker), Viv Werner (webmaster) and Dr. Michael Pro

Photo: Rob Kump

■ Maxine Colm, President of the Foundation introduced our honorees: Mark Goodman, the Chair of the GSF Finance Committee and Grace Renner, the Former Chair of the Fundraising Committee for their enormous contributions to the work of the Foundation

We were thrilled to have Amy Dixon, a famous Sommelier as our guest

speaker. Amy is known as the "Blind Sommelier" and was accompanied by her guide dog, Elvis. She is a Paralympic Athlete and wine expert who suffers from uveitic and neovascular glaucoma. Amy has been featured in the Wall Street Journal, New York Times, Fox News, and the Today Show.

We are deeply grateful for your support and with your help we can continue our work raising glaucoma awareness, supporting the medical fellows, and funding the glaucoma-related research projects.

We sincerely hope that you will be joining us next year. We will send out the "save the date" notices early, so you may mark our date on your calendars. ■

## EXCERPT FROM THE "CHAT HIGHLIGHTS" OF THE GLAUCOMA SERVICE WEBSITE

### Blood Flow and Glaucoma

Chat Highlights – June 4, 2014

Guest Speaker – Dr. Anand Mantravadi

Lorraine Miller – Editor, Chat Topic Researcher

Please refer to the following link for the entire chat.

<http://willsglaucoma.org/blood-flow-and-glaucoma-chat-highlights-june-4-2014>

**Moderator:** Welcome, Dr. Mantravadi. Thank you for joining us for our chat tonight on "Blood Flow and Glaucoma."

**P:** Good evening, Doctor. Would you please explain systemic blood flow and optic nerve head blood flow?

**Dr. Mantravadi:** Perfusion pressure of the eye is the difference between blood pressure (BP) and intraocular pressure (IOP). It is important for the physician to ask the patient if there is a history of low BP particularly at night in patients where the diagnosis of normal tension glaucoma is being considered. The perfusion pressure will likely be variable given that BP varies, IOP varies, and the measurement taken in an internist or ophthalmologist's office is probably a small window of the overall trend in perfusion pressure.

**P:** Would you also explain how blood flows through the eyes?

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## Blood Flow and Glaucoma / Chat Highlights June 4, 2014

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**Dr. Mantravadi:** Blood is sent to the eyeball from the heart. The terminal arteries and arterioles off the carotid artery feed the eye and perfuse the tissues. The veins will cycle this blood through the venous return system.

**P:** Should it be a standard practice for glaucoma patients to be asked about blood pressure or have their blood pressure taken at every office visit?

**Dr. Mantravadi:** We routinely will inquire about blood pressure for several reasons. Low BP or low diastolic BP has been associated with some types of glaucoma. Other studies have found an association between high BP with some types of glaucoma. High BP or hypertension can negatively impact the small blood vessels, arteries, and veins that feed the eye and may also contribute to secondary types of glaucoma. For those reasons, we do make it a practice to ask our glaucoma patients about their blood pressure.

**P:** There are mechanical and vascular theories that exist and both could be responsible for glaucoma. Would you explain them as they relate to glaucoma?

**Dr. Mantravadi:** Mechanical theories for glaucoma include the concept that increased eye pressure can cause stretching of the structural support system for the optic nerve causing cell damage and ultimately functional visual loss. The vascular theory supports glaucoma neuropathy as a consequence of insufficient blood flow into the eye due to high IOP or insufficient perfusion of the ocular tissues.

**P:** Are there treatment or prognosis implications if primary glaucoma has been diagnosed and the patient has fairly low blood pressure?

**Dr. Mantravadi:** Although there's evidence that low diastolic or perfusion pressure may have some role in progressive glaucoma, there is no scientific rationale to increase BP as this may have untoward consequences. Lowering intraocular pressure can

increase perfusion pressure to the eye.

**P:** What level, frequency, and type of exercise could help improve blood flow to the eye?

**Dr. Mantravadi:** Any mode of exercise that enhances cardiovascular fitness will promote good ocular blood flow.

**P:** Are there visual indirect signs of decreased blood flow that our glaucoma specialist views in our eyes?

**Dr. Mantravadi:** There are no specific indirect signs for low perfusion pressure alone. There may be signs of arteriolar hardening or narrowing in high BP states.

**P:** How is optic nerve head blood flow autoregulated? Does glaucoma affect this regulation process?

**Dr. Mantravadi:** It is thought that abnormalities in autoregulation can result from atherosclerosis or vasospastic disease. The abnormalities in autoregulation may contribute to lack of oxygen, tissue ischemia, and participate in optic nerve damage. This is part of the vascular theory that could be responsible for glaucoma.

**P:** Why does a reduction of ocular blood flow precede glaucomatous damage?

**Dr. Mantravadi:** I don't think we know the answer to that. If one ascribes to a vascular component of glaucomatous neuropathy, lack of blood flow induces ischemic injury that can lead to cell damage or loss, characteristic of glaucoma but the precise pathway is unclear.

**Moderator:** We would like to extend our appreciation to Dr. Mantravadi for joining us tonight and sharing his wealth of knowledge. ■



**GLAUCOMA SERVICE  
FOUNDATION TO PREVENT  
BLINDNESS**

Editor: Rita Stern  
Rita@mrs-stern.com

840 Walnut Street  
Philadelphia, PA 19107-5109  
215-928-3190  
www.willsglaucoma.org

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## CHAT SUPPORT GROUP

Join Moderators Vivian, Steve, and Brittany for a chat about glaucoma hosted by a glaucoma specialist.

**1st Wednesday of the month 8:30 pm – 9:30 pm**

*Hosted by a Wills Glaucoma Specialist*

For a complete schedule visit:

<http://willsglaucoma.org/chatsched.htm>



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in the enclosed envelope***