

Keynote Speech
OMICS 2013 Ophthalmology Research Conference
Christopher Hekimian, Dr. Sc. SE, MSEE

Good morning. I would like to thank the OMICS Group for this opportunity - - where an engineer, inventor and Stargardt's patient can address such a prestigious group of physicians from all over the world. Ever since I conceived of my system, the quantitative retina test grid, it's been one encouraging event after another. I'm deeply humbled.

Usually a speech like this begins with some kind of humorous anecdote. I've got a great mind for remembering jokes- - especially after a few drinks. But I think it's evidence of the seriousness with which people consider the sense of vision that I could not think of a single example of impaired vision humor. No matter how much I drank.

I was diagnosed with Stargardt's subsequent to a routine eye exam at a Lenscrafters. When the technician recommended that I contact a retina specialist, I had no idea why. Other than wearing glasses, it never occurred to me that I had any looming eye issues. Then I visited a retina specialist and I saw images of my retinae. I also used an Amsler grid for the first time. I was shocked to see parts of the grid drop away when I closed one eye... I was alarmed how the straight lines appeared wavy.

When I tell people about my eye condition I tell them to look at a telephone pole and to alternate closing your right and left eyes. If the pole looks like its doing a hula dance, then that's what it looks like to me.

Well, after that first visit I was told that I have the retinas of an 85 year old and the doctor didn't know how rapidly my condition would degrade, if at all. I was told to take preservative and to look into the Amsler grid once a month and to call the doctor if the grid changes noticeably.

All of my experiences with ophthalmologists since this instance have been positive (except when I return for a check-up). But on this day I felt let down as a patient. I was slowly going blind- - rate unknown- - and my instructions were to take vitamins and stare into a piece of paper. I didn't feel like that particular ophthalmologist was even curious as to what was happening to my retinae. It was a different doctor who diagnosed Stargardts. I was supposed to just leave my vision, my future, the futures of my family in the hands of this doctor-- and when things get real bad, I can make an appointment to see him.

I'm telling you that ophthalmologists are not unlike other physicians in that you have a tendency to underestimate your patients. For example, computers are a great assistive

technology for eye patients. Someone might need to suggest a tablet PC to your elderly patients. Let's assume that they could learn to use it to stay current with the news and to read books. Can you engage us a little more? Much of our frustration is rooted in fear and a sense of powerlessness. You might think we won't understand. You might think we won't be compliant. You might think that the technology will confuse us. You might think we don't want to know. One thing you should know is that for many, if not all of us, our overriding interest is to do whatever we can do to assist you in preserving our eyesight. Try us. Whatever we can do, give us the opportunity. When a patient has been diagnosed with a serious medical issue, nothing is worse than just sitting back and doing nothing, powerless to preserve your health. With me it was not knowing whether the next car that you buy will be your last or how many years you will be able to continue to do your job.

I've produced a short list of suggestions on how physicians like yourself might better engage with your patients.

1. Refer patients to resources and articles where they can learn more about their conditions. This is an expression of confidence in your patients intellectual ability that will challenge them to do their part to understand their condition and to replace some of their fear with a sense of determination.
2. Refer patients to blogs or other sources where they can get fast answers to FAQs. You might be able to provide them this directly. This kind of information will allay fears and help reinforce your instructions that can put the patient on their way to healthy vision care habits and practices that are within their control.
3. Advise patients of research studies that they might be able to participate in. It will be a comforting reminder to know that there are active studies going on. It will also reinforce the notion that your patient's experience with vision health challenges can contribute to a more general understanding of their disease and current treatment approaches.
4. In addition to viewing your patients as sensitive, intelligent human beings, don't forget that they are a data source too. Take advantage of your opportunities with them to ask probative questions. This kind of communication completes the link between your patient and medical science that you facilitate, and that they are depending on.
5. Encourage your patients to use a tool such as the Quantitative Retina Test Grid in order to collect and track their retina health metrics at home, between office visits. This will empower your patients and they will know that you and they are a team focused on the objective of preserving their vision health.

I'm a researcher. I've also volunteered for many research studies. Partly to observe different research techniques first hand, partly for money, partly to learn more about an issue or condition and partly to do a small part to advance science. It didn't make any sense to me to take a test every month without having an effective way of recording and

storing the test results so the data could be exploited over time. I decided to develop the quantitative retina test grid in order to satisfy my own desire to arrive at a prognosis for my own case that my doctors were uncomfortable in issuing. It never occurred to me that such a system would not have been available already. My system is only intended to replace a paper Amsler grid. But I think it goes a long way to empower patients so they can work alongside their doctors to learn more about their specific conditions. The notion that the system would tend to have promise in terms of supporting large scale clinical trials and research has not escaped me. I would expect that there would be tens of thousands of patients out there that would value the opportunity to offer their data for the cause of science. Especially while they are monitoring their vision health more closely and learning more about their condition. While I've been trying to market the system I've been adding more features. In addition to empowering the patient to monitor their condition more closely and to be able to share the data easily with their doctors, I've put in a binocular vision analyzer for safety's sake. I've also included an off-macula visualization trainer in order to help some people improve their quality of life. I've also developed a statistically rigorous trend analysis worksheet that is downloadable for free on my website. That tool supports hypothesis testing on the direction and magnitude of trends and the efficacy of treatments.

The doctors at NIH/NEI were surprised to have a patient that had no previous experiences with matters ophthalmological suggest a new way for patients to monitor their own retina health. I was an outsider to their world I guess. I'm an outsider to your world in a way. I've been very impressed how you treat outsiders. It's been an honor to meet and work with so many of you at trade shows or at your offices. What I mean is that you all have been willing to listen, and to consider a new idea with an open mind. You share your ideas and suggestions freely. In the current political climate you seem an oppressed group-- yet your focus is always your patient's eyesight-- not on politics. These are all great qualities that I noticed because they have been conspicuously absent in so many other fields that I've been exposed to. It has been an honor to be a guest in the world of ophthalmology. I hope that the quantitative retina test grid helps your patients collect and share useful information with you. With your skills and dedication and our desire to preserve our vision, maybe we can all work together to advance ophthalmological research and science.

Thank you for your time this morning and thank you for your efforts in helping me and others like me as you work to preserve our vision.