

PATIENT ADVOCACY BECOMES PERSONAL



An important piece of improving care and quality of life.

BY RICHIE KAHN, MPH

In the past few installments of this column, you've gotten to know a bit about my background as a patient, clinical trial participant, and clinical researcher. What we haven't discussed, however, is my primary focus in life: patient advocacy.

In fact, my first real professional job was in an advocacy role at the Hepatitis B Foundation, a nonprofit organization focused on finding a cure for hepatitis B and improving the quality of life of those affected by it. After moving on from that role, I spent the next decade pursuing a career in clinical research with patients at front of mind.

PUTTING PATIENT ADVOCACY TO WORK

In March 2019, I was diagnosed with what looked to be a pretty clear-cut, albeit early-onset, case of primary open-angle glaucoma. The first thing I did after sharing the news with my wife was put my advocacy hat back on and reach out to the Glaucoma Research Foundation. I figured, "Why not turn these lemons into lemonade?" If I could use my diagnosis to build awareness of the importance of screening for symptom-free vision loss and clinical research as a care option, it would be a net positive.

Over the next 2 years, I became heavily involved in advocacy and even mapped out a multiyear plan to transition from clinical research business development (ie, sales) to full-time advocacy work. I stayed busy reviewing and revising materials for patients and caregivers, keynoting the second annual Glaucoma Patient Summit and serving on the summit's steering committee, and facilitating patient and caregiver advisory boards for a number of organizations. More than anything, I firmly committed to helping patients become more effective advocates while also working to better incorporate patient preferences into the clinical development process.

ADVOCATING FOR ONESELF

For me, after my diagnosis, patient advocacy became personal. Eight months after the diagnosis, I flew from my

**"IF I COULD USE MY DIAGNOSIS TO
BUILD AWARENESS OF THE IMPORTANCE
OF SCREENING FOR SYMPTOM-FREE
VISION LOSS AND CLINICAL RESEARCH
AS A CARE OPTION, IT WOULD BE A
NET POSITIVE."**

home in Durham, North Carolina, to Philadelphia to get a second opinion. At that time, I learned that I had lost 15% of my vision, although my clinical signs appeared to be stable. The deeper we explored, the more questions arose. So, I kept pushing—advocating for myself.

I spent time with a neuro-ophthalmologist. I had MRIs taken to ensure that I didn't have a tumor and to confirm that I hadn't had a series of transient ischemic attacks, two potential explanations for the damage to my optic nerves. I even went through a battery of genetic tests that took several months to come back but ultimately provided answers.

Although I've now lost 50% of my vision and there are no viable treatments on the market, I have answers—I learned that my optic atrophy isn't caused by glaucoma but instead by Wolfram-like syndrome, a rare disease of the endoplasmic reticulum. My primary manifestation is optic atrophy, so it is treated like glaucoma. I am now doing my part to help bring an investigational product into the clinic.

ADVOCACY IN RESEARCH

Imagine that you're developing what you believe is a promising new therapeutic for glaucoma, one with fewer adverse drug reactions and less frequent drop administration required. The road to regulatory approval is

long and expensive, so it makes sense to smooth out the asphalt in front of you in any way possible. One way to do that is by listening to what patients have to say.

At the Patients as Partners conference in April, Kenneth A. Getz, MPH, Deputy Director of the Tufts Center for the Study of Drug Development, discussed the impact of patient advisory boards on clinical trial protocol design. He noted that incorporating changes advocated by patients tends to lead to the creation of more streamlined clinical studies.

For example, according to Mr. Getz, a typical phase 3 program that uses a patient advisory board has fewer endpoints, less burdensome eligibility criteria, fewer procedures performed per visit, a lower volume of data points collected, and fewer protocol amendments than a phase 3 program

ABOUT THE AUTHOR

Richie Kahn, MPH, is a health policy professional by training, clinical researcher by trade, and patient advisor by necessity. He is passionate about incorporating patient and caregiver perspectives into the clinical development process and ultimately reducing the time it takes to bring promising new therapeutics and diagnostics to market.

that doesn't incorporate a patient advisory board. Ultimately, this translates to shorter clinical development timelines and study budgets that are lower than anticipated.¹

ADVOCACY IN PRACTICE

How can physicians best incorporate the tenets of patient advocacy into

their practices? Listen carefully to your patients. Respond to them with empathy. Then, incorporate the lessons you learn into your next clinical encounter. When you don't have the answers your patients are looking for, don't be afraid to connect them with someone who might be able to help. Last but not least, remember that patients are invaluable members of your care team and should be treated with the respect they deserve. ■

1. Getz KA. Taking patient centrality to the next level in guiding protocol design. Presented virtually at: Patients as Partners; April 9, 2021.

RICHIE KAHN, MPH

- Health policy professional, clinical researcher, and patient advisor, Durham, North Carolina
- richardgkahn@gmail.com; Twitter and Instagram @rbaltikahn; linkedin.com/in/richiekahn
- Financial disclosure: None