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ay 14, 2010. I woke up to the room spinning. That day is forever etched in my mind. Firstly, because of the unfamiliar, sickening vertigo that rippled through my body, rendering me helpless. Secondly, because this symptom led to a cascade of events that four days later landed me in the ER diagnosed with a non-malignant brain tumor.

I was 33 years old, a wife and mother of a 4-year-old son. I went from being a routine patient to having to grasp the nuances of managing multiple medications, appointments, and specialists, on top of my own symptoms and fears. I lived 24/7 with the realities of my brain tumor, not just during the few minutes with my healthcare team during appointments. My diagnosis required a new level of coping and self-advocacy. I had to educate myself about new medications and treatments, seek second opinions when my treatment plan changed, and develop problem-solving skills I'd never needed before.

Two years after my diagnosis, my brain tumor doubled in size, causing my brain to swell. I needed emergency brain surgery. Medical error resulted in a delay in diagnosing the severity of my condition. This was pivotal in changing the trajectory of my life, both health and focus-wise. It took me 18 months to recover from the surgery with a resulting brain injury.

My patient experience of medical error

Becoming a Patient Partner

evoked strong feelings of anger and grief. As I recovered, this shifted to a passion to inspire people to put their health in their own hands. Having experienced the complexity of healthcare systems, I sought opportunities to collaborate for change and improvement.

I became a patient partner with my healthcare authority, started speaking at local and national conferences about my patient experience, and wrote a book, Two Steps Forward. I found a passionate and like-minded community of patient and health advocates that helped develop my knowledge and understanding of the power of the patient, family, and caregiver voice and its value in collaborating within healthcare.

Since my brain surgery, my laundry list of health conditions, medications, and experiences within the healthcare system have grown and fueled my passion for living my work. I continue to give input as a patient partner and engage in areas I feel offer opportunities for improvement. I now also work with healthcare systems and organizations on patient experience and patient activation. My passion is "the patient" and his or her journey, and what that means to the individual, their families, and caregivers. How we, the patient, experience our healthcare journey at every touch point has tremendous impact on our lives, both physically and emotionally. Who knew 10 years ago that my life would follow this path of lived experience?

The day-to-day and sometimes brutal realities of lived experience are not something that can be found in a textbook. The true essence and value of lived experience is found in the unique insight provided by these individuals. This insight, if authentically sourced through appropriate engagement, can lead to profound change and improvements for patients, systems, and the pharma and life-sciences industries. Profound change does not have to be of massive magnitude but can have a significant impact in my life as a patient. It's often the small things that count. For healthcare and pharma to be relevant, the lived experiences of patients and caregivers must be understood and integrated into the big picture, whether through storytelling or engagement activities, innovative technologies, or partnering with patients and their caregivers in other ways.

My patient experience is affected by all interactions across the continuum of my care, from a receptionist's call to my neurosurgeon's scalpel to discussions with my pharmacist about my medications. What better questions to ask me, the patient, than "What was your experience?" and "What matters to you?" to truly understand the complexity of the patient journey and how to co-create better outcomes.

WHAT PHARMA CAN LEARN FROM ME:

As an important part of the healthcare system, pharma already has a role in educating doctors and consumers about their products. Yet, further opportunities for finding pearls of wisdom exist within the stories not only of patients, but also their families and caregivers. Pharma can foster integration of those lived experiences by creating programs to engage with patients, families, and caregivers, and learn from their stories. Education can flow both ways, as people working in pharma and life sciences incorporate these learnings to provide true value.



IGNITE

2021 PharmaVOICE 100 Celebration

VIRTUAL EVENT

SEPTEMBER 9, 2021

SCHEDULE OF EVENTS

► Fireside Chat Panels

Casual conversations with PharmaVOICE 100s whose passions are ignited by purpose and blazing new frontiers

- 9-10am ET Sparks of Leadership
- 11-12pm ET Sparks of Creative
- 1-2pm ET Sparks of Innovation

► Igniting Change: The Red Jacket Panel

An in-depth conversation with our 2021 Red Jackets who shine their light on a transforming industry

• 3-4pm - A Panel of Red Jackets

Light it Up Happy Hour

Meet the PharmaVOICE 100s during a fun-filled hour of trivia and prizes

 4:30pm - Happy Hour with the PV100

(tentative schedule)



Join us as the PharmaVOICE 100 share how they spark inspiration, ignite change, and blaze new trails.

Celebrate their personal stories of success and learn what fuels their passion for the industry.

SPONSORSHIP OPPORTUNITIES

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*Event Sponsor Benefits

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Company branding on the event registration page

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Branding on OnDemand videos

Social media exposure



Company branding featured in an event wrap-up in the

October issue of PharmaVOICE

For more details or to secure a sponsorship, contact Lisa Banket, Publisher, at 609-730-0196 or lbanket@pharmavoice.com; Suzanne Besse at 561-465-5102 or sbesse@pharmavoice.com; or Amy Bishop at 267-374-8891 or abishop@pharmavoice.com.