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My Path to Advocacy

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My name is Grace, and I am a polio survivor from Nagpur, India. I was born in 1992 and adopted a year later in St. Louis. Having polio has always been a driving force in my life. I received the majority of my orthopedic care at Shriners Hospital in St. Louis—my passion for advocacy was sparked at Shriners. My two doctors were Perry Schoenecker, MD, and Eric Gordon, MD. Over the years, I had multiple surgeries such as leg lengthening and tendon releases. Thanks to them and my orthotist, Eric Crawford, I am able to walk with a KAFO brace and live a pretty independent life. Currently, I am a phlebotomist at a busy ophthalmology office!

My family was never shy about my polio diagnosis, but until I was in college, I did not necessarily understand the complexities of polio. When I was eight years old, my mom brought home *Small Steps, The Year I Got Polio* by Peg Kehret. I remember feeling terrified as my grandpa read this to me; I was too young to realize that I was not going to end up in an iron lung. Thankfully, my mom waited a few more years and read *Small Steps* to me again—I was significantly less scared the second time. Fortunately, I never experienced bullying in school, and I still am very open about living with a disability. A core belief of mine is education is key to prevention. When society forgets about polio, then we need to worry about a resurgence.

In high school, Shriners offered me a chance to be featured in their “Pre-Op Surgery” video. I’d be explaining to patients what they’d see and feel before their surgery; this is where my advocacy work truly began. I realized that I adored medical education and medical advocacy—making sure people feel comfortable and educated about their procedure, diagnosis or hospital stay is vital to recovery and long term outcomes.

This is how I became a Patient Ambassador for Shriners, speaking at the hospital and in public about my experience with polio and the importance of vaccines. I began to speak at events around St. Louis and news interviews.

Attending college and living on my own is when I truly discovered the intricacies of polio, specifically urinary tract and kidney infections due to my vagus nerve

being affected. I spent two years bouncing between specialists and undergoing testing to determine what was occurring. This caused me to begin to research and advocate for myself. I began to realize

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living with a disability was incredibly expensive, and I was so lucky to have parents who could help me out with the financial side of everything. I would not be where I am today without the support of my family, boyfriend and friends group.

Beyond having to advocate for myself in the healthcare system, I realized I could advocate for kids who have anti-vaxx parents. I wanted to reach these parents, and I wanted to prevent any other child

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from receiving a diagnosis of polio. I have always been active on social media and noticed that when I posted about polio, my engagement with posts would increase. This got me thinking about how I could use my social media presence to advocate for vaccines and prevent polio from coming back. I began posting on Facebook and Twitter about having polio. People noticed. In 2018, I was approached by Erin and Erin, host of

This Podcast Will Kill You, for an interview. We talked about the medical and social issues surrounding disability. I began to realize more and more just how lucky I am and how badly our healthcare system needs an overhaul.

Polio survivors have one of the most unique perspectives on vaccines and COVID-19. We have experienced a vaccine preventable disease (VPD) and cannot fathom why someone would refuse a vaccine for another VPD. During the COVID-19 pandemic, I ramped up my advocacy work, reaching out to news organizations, medical professionals, and posting in Facebook groups.

I realized that I needed to use my voice and privilege to advocate for the COVID vaccines. One of my favorite ways to network with others is an “Ask Me Anything” post in large Facebook groups. This has allowed me to meet multiple people within public health and educate people about polio.

Living with polio has affected every area of my life, but I would not change it for anything. I am honored to use my voice to advocate for children who have anti-vaxx parents, to provide education to families about vaccines, and hopefully to prevent anybody else from contracting polio. ■



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Post-Polio Health International's mission is to collect, preserve and make available research and knowledge to promote the well-being and independence of polio survivors, home ventilator users, their caregivers and families, and to support the health professionals who treat them.

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