CRITICAL PATH INSTITUTE

Bending the Curve: Sarah Zenner-Dolan’s Advocacy Journey with Parkinson’s Disease

Sarah Zenner-Dolan speaks at C-Path’s 20th Anniversary Event in Tucson.

My personal mission in fighting Parkinson’s is to be in the best physical, mental, and emotional shape I can so that I am a candidate for a medical breakthrough when it comes. This mission is how I stay focused on bending the curve of this insidious disease.

Long before my diagnosis on September 5, 2018, I began experiencing symptoms associated with the prodromal phase of Parkinson’s Disease. Phantom odors, constipation, and poor sleep started about ten years prior to diagnosis. Added to that list I began noticing anxiety, a twitch in my right hand, a tremor in my lower calf, and difficulty with tasks like brushing my teeth and handwriting. Three years before my diagnosis, as these symptoms were worsening, I developed painful rigidity and leg cramps. It was my acupuncturist who urged me to seek a neurological evaluation.

The diagnosis was a shock. The neurologist observed rigidity, tremors — including a tongue tremor — and a lack of arm swing. I had assumed I had Essential Tremor, not Parkinson’s, which I wrongly labeled as a syndrome that only old men faced. This revelation marked the beginning of my proactive approach to managing my disease.

I explored clinical trials, attended meetups, and engaged in various exercises like Rock Steady Boxing, Pilates, spin classes, yoga, and hiking. Despite my best efforts, progressive symptoms forced me to leave my job of 30 years. As a single mom of three, this was a significant adjustment. However, I found new purpose as a Davis Phinney Foundation Ambassador and began riding with them on Team DPF, as well as participating in clinical trials, which has been a significant part of my journey with Parkinson’s disease. I was excited to contribute to research and to do something positive with my diagnosis.

On July 16, 2022, I met Diane Stephenson, C-Path’s Vice President of Neurology and Executive Director of its Critical Path for Parkinson’s consortium. Diane, her husband Joe, and her sister Stephanie had traveled to Longmont, Colorado to ride in The Davis Phinney Foundation Tour de Victory. After crossing the finish line, we happened to sit next to each other at the post-ride lunch. I did not know who I was chatting away with, sharing my whole story of why I was doing a Parkinson’s fundraising ride. Later that day our friend Kevin Kwok suggested I meet Diane because he saw potential collaboration opportunities.

Sarah with Diane (far left) C-Path CEO Klaus Romero (far right) and Klaus' wife (middle right) at the Tucson 20th Anniversary Event.

Unbeknownst to me I had already met Diane! We hit it off, and quickly I was integrated onto the CPP Endpoints team and was given an opportunity to share my experiences living with Parkinson's and as a clinical trial participant. This information proved valuable and launched me in a personal direction I could never have imagined.

At the C-Path Annual Meeting in Washington, DC, in November 2023 alongside a young woman with Alzheimer's Disease, we shared our experiences living with the two of the most prevalent brain diseases. The room was filled with preeminent thought leaders from around the world: top neurological researchers and clinicians, the FDA, EMA,, neurology industry leaders, top brass from patient advocacy groups such as the Michael J. Fox Foundation, Alzheimer's Association, Parkinson's Foundation and more. It was my first time publicly telling my story of living with Parkinson's from diagnosis to participating in clinical trials. The audience's interest was palpable. Many questions were asked, and it was very exciting. Living true to the C-Path mission of patient-centric work, C-Path CEO Klaus Romero and the rest of the team reworked the afternoon schedule to extend our session, so every audience question was answered.

It's truly remarkable how opportunities beget additional opportunities. From that presentation came many more chances to make a difference with my voice. The FDA Peripheral and Central Nervous System leadership team was at that Annual C-Path Meeting, and after my presentation we established my interest in any and all opportunities to make a difference. I learned they had an opening for a member on their Advisory Committee (Ad Com), applied for it and was accepted. Next thing I knew I was attending the Ad Com meeting to review the application for Donanemab, a medication used to treat early-stage Alzheimer's disease which was subsequently FDA-approved for commercial use. Again, I had found myself in a position to be a voice for so many others.

Along the way, Diane and I were invited to be keynote panelists at the125th annual meeting of the American Society for Clinical Pharmacology and Therapeutics in March 2024, where we shared with the 2,000 attendees the importance of meaningful patient-centric clinical endpoints and the need for digital biomarkers in Parkinson's trials. The takeaway from our session was that in clinical research, patients are participants and partners, not passengers.

My personal mission of living my best today is buoyed by the trust I have in the behind-the-scenes work of the brilliant teams at Critical Path Institute. I thank you for all you are doing to efficiently and effectively integrate the research, regulatory, clinical, industry, and advocacy communities to bring us the breakthroughs that we so desperately need. I am looking forward to a very bright future.