

## Active Lifestyles Key for Parkinson's Advocates Zenner-Dolan, Kwok as They Await Advancements in Treatments

By Alexander Diegel

Dr. Kevin Kwok and Sarah Zenner-Dolan are drawn together by more than their respective experiences living with Parkinson's disease (PD). Both have stepped up as champions for those living with PD, contributing to discussions with industry and nonprofits to ensure the patient voice is heard and incorporated into drug development for this condition. They have also not allowed the neurological disorder that affects more than 10 million people worldwide keep them confined or sedentary; on the contrary, they have committed to active lifestyles, adding exercise and fitness activities to maintain vitality in their daily routines post-diagnosis.



After 25+ years spent living in San Francisco with a career in biopharmaceutical operations, Kwok (left, with C-Path's Diane Stephenson, middle) moved to Colorado, where he could immerse himself in the exact vibrant, outdoor lifestyle that is imbued with adventure and activity in the Rocky Mountains. Kwok is also a board member for the Davis Phinney Foundation for Parkinson's, which includes "Inspire Action," as one of its core tenets. The nonprofit routinely hosts cycling events and fundraisers on behalf of the PD community.

Zenner-Dolan has made similar lifestyle changes that included adding cycling, boxing classes, yoga, and more to her routine. For Sarah, it's about a "mission to

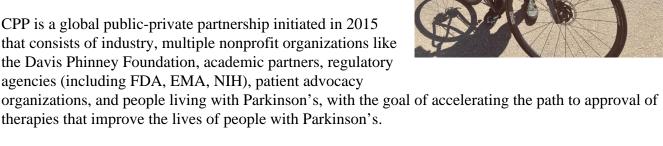
be in the best physical, mental, and emotional shape, so that I am a candidate for a medical breakthrough when it comes."

Zenner-Dolan is diligent in her concerted effort to stay self-informed of her lived experience. She created a daily log that records how she is feeling emotionally, as well as to record her physical activity. "I assign myself a color, a red, yellow, or green, based on how I feel that day. Red means bad. Green means a good day, and I can tell you that there are always correlations between not exercising and a red day. It's been a really good accountability partner for me," she explained.

It was, in fact, at one of the Davis Phinney Foundation's cycling events in July of 2022 that Zenner-Dolan met Dr. Diane Stephenson, C-Path's Executive Director of its Critical Path for Parkinson's (CPP) consortium.

From there, Sarah's portfolio as a patient advocate has only grown; she has since become an advisor at C-Path and was a featured keynote speaker at the organization's 2023 Neuroscience Annual Meeting, where she bravely described to attendees what her symptoms — phantom odors, lack of sleep and chronic fatigue, pain in the legs and adductors — were like years before her diagnosis. Zenner-Dolan (right, at a cycling event like the one she met Stephenson at) also described the importance of clinical trials and her experiences taking part in them. (Sarah's session starts at 3:23:23 here). Kwok, too has been involved with CPP, and co-published a manuscript along with Stephenson, additional members of the C-Path team, and others living with neurological disorders.

CPP is a global public-private partnership initiated in 2015 that consists of industry, multiple nonprofit organizations like the Davis Phinney Foundation, academic partners, regulatory agencies (including FDA, EMA, NIH), patient advocacy



"The voice of people with lived experience is now front and center to drug developers, thanks to the FDA's patient-focused drug development initiative," explained Stephenson. "Both Kevin and Sarah's unique perspectives are shaping how to think differently about endpoints and clinical trials."

The program's focus is to broadly advance the drug development landscape for Parkinson's prevention and treatment. By working collaboratively with global PD stakeholders, CPP is sharing data, knowledge, and

resources that enhance the development and regulatory endorsement of novel medicines and tools.



Sarah and Diane, middle left, at ASCPT 2024 in March.

In addition to its focus on broadening populations for clinical trial recruitment, the collection and analysis of real-world data, and its support of innovative technologies, CPP continues to give people with lived

experiences and advocates like Kwok and Zenner-Dolan platforms to ensure their experiences are heard by regulators and others doing the work to advance treatments in Parkinson's.

In October of last year, C-Path founded a Parkinsons's Advisory Council comprised of those living with Parkinson's and their care partners, with diverse representation across the U.S., Canada, Europe, and the UK. With support from CPP's nonprofit organizations, including the Michael J. Fox Foundation, Parkinson's Foundation, Cure Parkinson's Parkinson's Canada, Parkinson's UK, and Parkinson's Europe, the Council meets quarterly to address clinically meaningful outcomes — endpoints or measures that describes how an individual feels, functions, or survives — for use in PD clinical trials.

Through empowerment and amplification of the voice of lived experience, as well as the "right drug, right patient, right time" approach, CPP will continue to develop strategic partnerships for collaborations that accelerate the path to data-driven drug development aimed to enhance the lives of people with Parkinson's. Together.

Want to support CPP's life-changing work?

## Get in Touch



Kevin with C-Path CEO Dr. Klaus Romero (right).