From Diagnosis to Advocacy: Layne Oliff's Unwavering Commitment to ALS Awareness and Action

By Alexander Diegel

Layne Oliff was an active runner who successfully completed 10-mile trail runs up until his 60th birthday — before he was diagnosed with amyotrophic lateral sclerosis (ALS) in November of 2020. Layne soon pivoted that same drive and commitment to another journey, as an active advocate in the ALS community.

ALS Advocate Layne Oliff

"When I was diagnosed, I right away started to look into organizations where I could be an advocate, help, and learn," explained Layne. "I started working with I AM ALS. Through that organization I learned more about ALS research and met many other people."

Though he stays as physically active as he can with regular sessions on the exercise bike, the disease that weakens muscles and breaks down physical function has taken its toll. It has progressed in Layne to the point that he needs help from his wife and primary caregiver Ann for most daily activities and has robbed him of much of his upper body strength. But his legs and core remain strong, as well as his resolve to make a difference and advance treatments in the disease that affects over 200,000 people worldwide.

"My biggest advocacy effort is really to get the larger ALS organizations to work together and move in one direction. When I was initially diagnosed, ACT for ALS had not yet passed. That was the big push, to help get passage of the ACT. Hundreds of people helped to get this bill passed and there are thousands of people that it will now affect."

The ACT for ALS (Accelerating Access to Critical Therapies for ALS Act) was passed in 2021. It required the Department of Health and Human Services, through FDA and NIH, to implement a public-private partnership for rare neurodegenerative diseases (RNDs) that utilizes cooperative agreements to advance the understanding of neurodegenerative diseases and foster development of treatments for ALS and other RNDs.

The result was the launch of C-Path's Critical Path for Rare Neurodegenerative Diseases (CP-RND) program in September of 2022. CP-RND is a public-private partnership that leads collaborations to advance treatments that improve the lives of those affected by RNDs, including ALS.

CP-RND is focused on working with stakeholders (people with ALS, caregivers, gene carriers, clinicians, pharmaceutical companies, researchers, NIH and FDA) to increase the understanding of disease pathogenesis and natural history by quantifying disease progression. These efforts include evaluating potential biomarkers from patient-level data and optimizing clinical trial design, including exploration of innovative trial designs

and clinical outcome assessments, to improve the efficiency and success of drug development.

This, together with the capabilities of C-Path's Rare Disease Cures Accelerator-Data and Analytics Platform (RDCA-DAP), integrates multiple patient-level data sources across rare diseases, providing the foundation for leveraging advances in basic and clinical sciences.

"By bringing such diverse stakeholders and talents together, initiatives like CP-RND represent a unique opportunity to support the ALS, and other RND communities, in developing efficient solutions to unmet needs in clinical trials," stressed Collin Hovinga, Pharm.D., Vice President Rare and Orphan Disease Programs at C-Path. "Involving people with lived experience in every aspect of our work is essential to the success of these efforts and we are so appreciative of Layne and the RND community for their support."

As organizations like C-Path work to advance treatments for those living with ALS, Layne has a message of hope and empathy, and expresses a need for researchers to listen to the voice of the patient.

"I think more researchers need to talk to people with lived experience to understand what they're going through and understand the needs of the community. I hope that research leads to therapies that can cure or stabilize the disease, and that C-Path can help in that process. We are on "ALS time" but know it's not going to be tomorrow, it may be three years, five years, 10 years, but hopefully C-Path will be critical in that process," he explained.

While acknowledging the difficulty of the fight, Layne shared a final message for all of those working in, and living with, ALS. "Stay motivated and stay positive. Stay focused on the end goal, don't dawdle, stay strong, and keep on plugging away. We will achieve our goal."

Want to support CP-RND's life-changing work?

get in touch