

C-Path Honors Memory, Legacy of Beloved CP-RND Member and ALS Patient Advocate Layne Oliff



Critical Path Institute (C-Path) mourns the loss of one of its ALS community members, Layne Oliff. Layne, who passed on Friday, April 11, at the age of 65, was diagnosed with ALS in November of 2020.

Layne was a dedicated patient-advocate and member of C-Path's Critical Path for Rare Neurodegenerative Diseases (CP-RND) consortium, a regular at organization events, a guest speaker at C-Path's inaugural Global Impact Conference in 2024, and the subject of a [C-Path impact story](#) last year during ALS Awareness Month.

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

"Layne's approach to advocacy reflected his skill in completing races; he was dedicated, determined, collaborative, and kind," said CP-RND Director of Outreach Thom Hart. "Just like the racecourse, he set a pace that pushed us all forward, teaching us all a lot about what was possible and how working together propelled us all further ahead."

Layne was a key voice in getting the [ACT for ALS \[Accelerating Access to Critical Therapies for ALS Act\]](#) passed and pointed to that as his biggest advocacy effort and a vital piece of his legacy. Passed in 2021, ACT for ALS 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.



Thom and Layne (seated left and middle) at C-Path's Global Impact Conference in 2024 during the ALS Patient Advocacy panel.

That partnership became known as CP-RND, which launched in September of 2022 with a mission to lead collaborations that advance treatments and improve lives of those affected by rare neurodegenerative diseases, including ALS.

"I don't have enough sentiments to express regarding Layne," said Collin Hovinga, C-Path Rare/Orphan and Pediatric Disease Programs Vice President. "He was such a positive impact on everyone around him. He was extremely selfless in sharing his life and inspiration. I learned so much in getting to know Layne; seeing him and his wife at meetings always made my day, he was such a shining light."

"C-Path is honored to work with such brave and dedicated patient advocates like Layne. We will miss his drive, passion, and wit," said C-Path CEO Klaus Romero. "We offer our thoughts and condolences for his family."

At his family's request, donations in Layne's memory may be made to Compassionate Care ALS (www.ccals.org), NEALS: Northeast Amyotrophic Lateral Sclerosis Consortium (www.neals.org) and Hope Loves Company (www.hopelovescompany.org).

As we remember Layne, we would like to share this powerful interview from our 2024 Conference.