

Moving Treatments Across the Finish Line: A Focus for ALS Awareness Month

Twenty-four years ago,
Fernando Vieira lost his best
friend



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to amyotrophic lateral sclerosis (ALS). Driven by that loss, he joined the ALS Therapy Development Institute (ALS TDI). His first boss at the research lab was a man living with the disease. Every day, individuals living with ALS came through the laboratory, deeply embedding their lived experience into the organization's DNA. Vieira, who is now the CEO and Chief Science Officer of ALS TDI, says this proximity creates a galvanizing tension that grounds the science in human reality.

But this deep integration of the patient experience has not always been the standard in drug development. For decades, the global research ecosystem operated on a paternalistic model. Medical professionals and drug developers talked to the patient community rather than speaking with them. As families face the relentless progression of neurodegenerative conditions, working in isolated silos wastes the most precious resource available time.

That landscape is finally shifting.

During the “Today’s Voices, Tomorrow’s Treatments” panel discussion at the 2025 C-Path Global Impact Conference, scientific leaders and patient advocates highlighted a growing recognition that clinical breakthroughs must begin with the lived experience. Vieira explained that while engaging directly with patients can feel jarring for a bench scientist focused on incremental laboratory work, it is absolutely essential. Direct dialogue forces researchers out of their comfort zones to ensure their biological models remain relevant to the people they intend to serve. Watch the full panel discussion [here](#), a conversation worth watching for anyone working in or affected by neurodegenerative disease.

The complexity of neurodegenerative disease itself shapes what good evidence looks like. Penny Dacks, Chief Science Officer for the Association for Frontotemporal Degeneration, noted during the panel that up to 30 percent of individuals diagnosed with ALS also experience frontotemporal dementia. This overlap has direct consequences for drug development: clinical trials that fail to account for cognitive and behavioral symptoms risk measuring the wrong outcomes, enrolling the wrong patients, or missing meaningful signals entirely.

This cognitive overlay presents a distinct hurdle for researchers trying to measure the impact of the disease. As cognitive and behavioral symptoms can impact a person's ability to engage in traditional public advocacy, their experiences are frequently missing from the broader conversation; their daily struggles often remaining hidden from traditional clinical trial metrics. To capture the full breadth of experiences, the research community must actively gather insights from care partners and look beyond the most visible patient perspectives.

Health experts and regulatory science organizations are stepping in to address this exact challenge. The Critical Path for Rare Neurodegenerative Diseases (CP-RND) and Clinical Outcome Assessment (COA) programs at C-Path work directly with the FDA, ALS researchers, and patient communities to develop and refine robust, validated tools that can be reliably used to assess new treatments in ALS. Without appropriate outcome measures, even a promising drug can stall before it reaches patients. This pre-competitive, collaborative approach ensures the ALS community has the tools it needs for successful clinical trials and drugs that improve the lives of people with ALS. This work extends across the neurodegenerative disease landscape, including Huntington's disease, Parkinson's disease, and Alzheimer's disease, making C-Path a critical convener and catalyst across neurodegenerative diseases.

Grounding clinical data in the daily reality of the disease is the only way to accelerate new treatments. As the global community marks May as ALS Awareness Month, the message from advocates and researchers is clear: translating the lived experience of ALS into measurable, regulatory-grade evidence is the only way to bring those treatments across the finish line.

These conversations are not stopping here. Join us at the [2026 C-Path Global Impact Conference](#) this September, where researchers, regulators, and patient advocates will once again come together to accelerate the path from discovery to treatment.