

ALS Awareness Month: Connecting the Dots in ALS Research

A single clinical study can generate millions of data points. For more than a year, people living with amyotrophic lateral sclerosis (ALS) in an ALS Therapy Development Institute study wore motion sensors on their arms and legs for one full week every month. Tracking daily physical decline over that extended period produced one of the largest actigraphy datasets ever assembled. However, translating a dataset of this size into approved treatments presents an entirely different hurdle. Pharmaceutical companies have historically struggled to use wearable technology in official trials. Because developers lacked a clear framework for submission, continuous measurements rarely factored into final regulatory approval processes.



Seeking a solution to these regulatory roadblocks, ALS Therapy Development Institute leaders shared their actigraphy data with Critical Path Institute® (C-Path). Collin Hovinga, Pharm.D., M.S., FCCP, Vice President for Rare/Orphan and Pediatric Disease Programs at C-Path, currently oversees a working group analyzing these specific metrics. By standardizing the information, his team's goal is to help FDA officials accept wearable sensor data as concrete evidence in future clinical trials.

An aggressive biological timeline defines ALS. Most individuals succumb to the condition within three to four years of their initial diagnosis. Spontaneous cases account for roughly 90 to 95 percent of these diagnoses, leaving those affected reliant on therapies that barely slow physical decline. Choosing to spend their limited remaining months participating in actigraphy studies allowed these individuals to generate vital evidence for generations diagnosed after them.

Urgency of this scale eventually forced a complete overhaul of how federal agencies approach rare diseases. Passing the Accelerating Access to Critical Therapies for ALS Act on December 23, 2021, allowed lawmakers to inject \$100 million annually into the research ecosystem. Mandates within the act required FDA and NIH teams to build public-private partnerships covering rare neurodegenerative diseases. Securing grant funding to lead this initiative, C-Path established the Critical Path for Rare Neurodegenerative Diseases program.

Under the neurodegenerative disease umbrella, C-Path co-stewards the ALS Knowledge Portal infrastructure with the NIH and helps shape regulatory endpoints for the [ALL ALS](#) natural history study. Digital health technology working groups, including the teams analyzing the actigraphy data, sit directly inside this program.

C-Path seamlessly integrates this targeted neurodegenerative research with its Rare Disease Cures Accelerator Data and Analytics Platform (RDCA-DAP®). Launched in 2019 in partnership with the FDA and the National Organization for Rare Disorders, this platform aggregates information from registries, natural history studies, and clinical trials to make it standardized and reusable across global research

communities.

Reusing curated information prevents researchers from wasting years recreating foundational knowledge. Hovinga recently addressed this urgency during an episode of [The Critical Path Institute Podcast](#), noting that every precious data point counts.

“Having to redo something means another year, two years, three years that passes before you have evidence to support a decision,” he explained.

ALS Awareness Month serves as a vital moment to acknowledge the people driving this science forward.

“You have a very progressive disease, but these people see the value of this and are willing to give their time and insights to support things that will benefit people even beyond their lifespan,” Hovinga said.

Collaborative initiatives like these ensure that no data point is ever wasted. Platforms like RDCA-DAP and CP-RND standardize and preserve research so scientists can build directly on what came before, skipping the years it would otherwise take to reconstruct baseline infrastructure for every new study. But that foundation only grows stronger with each new participant who chooses to contribute. Every person who joins a study adds to a collective resource that outlasts their own involvement, accelerating the path to treatments for everyone diagnosed after them.

To learn more about C-Path’s broader work in neurodegenerative diseases, visit C-Path’s [Rare and Orphan Disease program](#) web pages. And join the conversation in person at the [2026 C-Path Global Impact Conference](#) this September.