C-Path and AFTD Partner to Bring Frontotemporal Degeneration Data into Rare Disease Data Platform for the First Time

Collaboration through C-Path's Critical Path for Rare Neurodegenerative Diseases partnership will enable research spanning frontotemporal degeneration and ALS, with four biopharmaceutical companies contributing data at launch.

TUCSON, Ariz., Nov. 10, 2026 — Critical Path Institute® (C-Path) and the Association for Frontotemporal Degeneration (AFTD) today announced a new data-sharing collaboration marking the first integration of frontotemporal degeneration (FTD) data into C-Path's Rare Disease Cures Accelerator–Data and Analytics Platform (RDCA-DAP®). Bringing FTD data into the same harmonized, standardized format as data from amyotrophic lateral sclerosis (ALS) and other rare neurodegenerative diseases will facilitate a more actionable understanding of disease progression across these conditions, generating evidence that can accelerate drug development and support regulatory decision-making. The collaboration is organized through C-Path's Critical Path for Rare Neurodegenerative Diseases (CP-RND) partnership, established in response to the Accelerating Access to Critical Therapies for ALS Act (ACT for ALS).

Data-sharing agreements are in place with four biopharmaceutical companies: Alector, Denali Therapeutics, Passage Bio and Transposon Therapeutics, each of which has agreed to make patient-level control arm clinical trial data available to the broader research community. The data are now being curated and are expected to be available to qualified researchers through the RDCA-DAP data access request process in the coming months.

CP-RND's mission extends across rare neurodegenerative diseases, in keeping with the mandate of ACT for ALS. Researchers increasingly recognize ALS and FTD as related conditions that can share genetic, biological and clinical features. People diagnosed with either condition sometimes develop clinical manifestations of the other as their disease progresses, a combined presentation often referred to as ALS-FTD.

"RDCA-DAP has brought together patient-level clinical trial and natural history data across many rare diseases, including ALS, progressive supranuclear palsy and VCP-associated multisystem proteinopathy," said Collin Hovinga, Pharm.D., Senior Vice President of Rare/Orphan and Pediatric Disease Programs at C-Path. "When a trial ends or a study's funding concludes, the maximum value of those data would otherwise be lost, along with the contributions of the people living with these diseases who made it possible. We're grateful to AFTD and to the companies that have shared their FTD data to help prevent that. Access to FTD clinical trial data empowers researchers and drug developers to ask important scientific questions that can meaningfully inform future drug development programs."

"There is an urgent need for effective treatments for this devastating disease that robs people of their abilities and profoundly affects families," said Penny Dacks, Ph.D., AFTD's Chief Scientific Officer. "Promising therapies are ready for clinical testing, but gaps in historical data make it harder to design trials that yield conclusive results. By sharing their trial data, these four companies are helping researchers design stronger studies while honoring the contributions of all trial participants. They also create a precedent of data sharing that can be built upon with future programs. On behalf of everyone urgently awaiting treatments, we thank

them and our partners at the Critical Path Institute's RDCA-DAP."

"Families affected by FTD have participated in our clinical studies in the hope that what we learn goes further than any single individual program," said Arnon Rosenthal, Ph.D., Chief Executive Officer of Alector. "Contributing this data to RDCA-DAP honors that commitment. We're grateful to our co-development partner GSK, to the participants and investigators and to C-Path and AFTD for building a resource the whole field can draw on."

"Individuals and families living with FTD urgently need treatments that can slow the progression of this devastating disease," said Richard Tsai, Ph.D., Executive Medical Director, Early Clinical Development at Denali Therapeutics. "Every patient participating in a clinical trial contributes important information that can help move the entire field forward. By sharing data through this collaboration with C-Path and AFTD, we can extend the impact of their contributions beyond a single study, deepening our collective understanding of disease progression and accelerating the advancement of potential treatments."

"We are delighted to contribute our FTD clinical trial data to RDCA-DAP," said Andrew Satlin, M.D., Chief Medical Officer at Transposon Therapeutics. "We strongly support the work that C-Path and AFTD are doing to advance research on treatments for individuals and families living with FTD."

Organizations interested in contributing FTD or other rare disease data to RDCA-DAP and researchers who wish to be notified when the FTD data become available can visit c-path.org/rdca-dap or email rdcadap@c-path.org.

About Critical Path Institute
Founded in 2005, as a public-private partnership in response to the FDA's Critical Path Initiative, C-Path's mission is to lead collaborations that advance better treatments for people worldwide. Globally recognized as a pioneer in accelerating drug development, C-Path has established numerous international consortia, programs and initiatives that currently include more than 1,600 scientists and representatives from government and regulatory agencies, academia, patient organizations, disease foundations and pharmaceutical and biotech companies. With dedicated team members located throughout the world, C-Path's global headquarters is located in Tucson, Arizona and C-Path's Europe subsidiary is headquartered in Amsterdam, Netherlands. For more information, visit c-path.org.

Critical Path Institute is supported by the Food and Drug Administration (FDA) of the Department of Health and Human Services (HHS) and is 43% funded by the FDA/HHS, totaling $20,724,703, and 57% funded by non-government source(s), totaling $27,346,613. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement by, FDA/HHS or the U.S. Government.

About Critical Path for Rare Neurodegenerative Diseases
CP-RND is a public-private partnership established in September 2022 in response to Section 3 of the ACT for ALS. With support from FDA and the National Institutes of Health (NIH), CP-RND brings together industry partners, nonprofit organizations, academic researchers and people with lived experience to accelerate the development of safe and effective treatments for ALS and other rare neurodegenerative diseases. For more information, visit c-path.org/cp-rnd.

About the Association for Frontotemporal Degeneration (AFTD)

The Association for Frontotemporal Degeneration (AFTD) is the leading nonprofit organization dedicated to improving the quality of life of people affected by frontotemporal degeneration (FTD) and driving research toward a cure. AFTD advances research, raises awareness, educates healthcare professionals, provides support for individuals and families, and advocates for public policies that promote earlier diagnosis, better care, and increased research funding.

Guided by the values of knowledge, compassion, collaboration, respect, and dignity, AFTD brings together people affected by FTD, healthcare professionals, researchers, volunteers, and advocates to accelerate progress and ensure that no one faces FTD alone.

Media Contacts:
Roxan Triolo Olivas
C-Path
520.954.1634
rolivas@c-path.org

Kissy Black
C-Path
615.310.1894
kblack@c-path.org