

C-Path and EFACTS Announce Data Sharing Agreement Making RDCA-DAP the Largest Worldwide Database for Friedreich's Ataxia

TUCSON, Ariz., Nov. 10, 2022 — [Critical Path Institute \(C-Path\)](#) and the [European Friedreich's Ataxia Consortium for Translational Studies \(EFACTS\)](#) today announced a data sharing agreement to incorporate patient data into C-Path's [Rare Disease Cures Accelerator-Data and Analytics Platform \(RDCA-DAP®\)](#) solidifying RDCA-DAP as the largest worldwide database for Friedreich's ataxia.

The integration of these data allows for a broader and more comprehensive understanding of the rare autosomal recessive neurological disease, Friedreich's ataxia (FA), while also helping to eliminate data silos and ensuring the data is utilized to its fullest extent. This is particularly important in rare diseases like FA, a severely debilitating disease that leads to the loss of the ability to walk and affects dependency for all activities. Some patients may also have cardiomyopathy that can cause premature death, visual and auditory loss, kyphoscoliosis, pes cavus and diabetes.

C-Path's RDCA-DAP provides a centralized and standardized infrastructure to support and accelerate rare disease characterization targeted for clinical development. Additionally, the platform advances best practices to help enhance future data collections, including natural history studies, with attention to established data quality standards, in order to be most useful to clinical trial design and regulatory review. It includes a robust, integrated database and analytics hub that allows for the aggregation of rare disease data from various sources and the efficient and effective interrogation of that data.

“Partnering with EFACTS is a huge step in the advancement of Friedreich's ataxia research,” said RDCA-DAP Scientific Director Alexandre Bétourné, Pharm.D., Ph.D. “The addition of EFACTS data to our FA database is instrumental to continue our advancement of solutions to facilitate medical product development for FA and will enable additional efforts and discoveries. Making these data available to leading researchers for advanced analysis on the RDCA-DAP platform will empower clinicians and researchers to make leaps in progress towards one day finding a cure.”

“The Friedreich's Ataxia Research Alliance (FARA) partnered with C-Path to create a database that could integrate data from natural history studies and clinical trials, FA Integrated Clinical Database (FA-ICD), and we are really excited that this data is now part of RDCA-DAP and that our EFACTS partners are also contributing such informative data,” said FARA CEO Jennifer Farmer, M.S. “The collaboration with EFACTS goes beyond the contribution of this important data as EFACTS concomitantly joins the steering committee of the C-Path's taskforce for FA and will inform new research. We look forward to the new insights and clinical trial tools that will be derived from having such a robust database shared with the research community.”



The EFACTS patient registry is a multi-centre, multi-national observational study. It was initially funded by the 'Seventh framework programme' of the European Union. EFACTS' strength lies in its collaborative approach, providing an extensive clinical and biological data repository to facilitate studies that could not otherwise have been possible.

“The contribution of EFACTS data and the active participation in the C-Path project will empower Friedreich’s ataxia research world-wide to broaden knowledge about the natural course of FA,” said Sylvia Boesch, M.D., Department of Neurology, Medical University Innsbruck. “Moreover, it will facilitate future clinical studies which are the basis for further development of medication and treatment options for all FA patients.”



About Critical Path Institute

Critical Path Institute (C-Path) is an independent, nonprofit organization established in 2005 as a public and private partnership. C-Path’s mission is to catalyze the development of new approaches that advance medical innovation and regulatory science, accelerating the path to a healthier world. An international leader in forming collaborations, C-Path has established numerous global consortia that currently include more than 1,600 scientists from government and regulatory agencies, academia, patient organizations, disease foundations, and hundreds of pharmaceutical and biotech companies. C-Path U.S. is headquartered in Tucson, Arizona, [C-Path in Europe](#) is headquartered in Amsterdam, Netherlands and [C-Path Ltd.](#) operates from Dublin, Ireland with additional staff in multiple other locations. 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 55% funded by the FDA/HHS, totaling \$17,612,250, and 45% funded by non-government source(s), totaling \$14,203,111. 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.

Media Contact:

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