

Sanford Health Rare Disease Data Registry Partners with C-Path's RDCA-DAP, Cure Mito Foundation to Aggregate Rare Disease Data in Platform

TUCSON, Ariz., July 12, 2023 — [Critical Path Institute](#) (C-Path) announced today that the Coordination of Rare Diseases based at Sanford Research (CoRDS), in partnership with Cure MITO, will contribute its mitochondrial disorders data from its international patient registry to the C-Path-managed Rare Disease Cures Accelerator-Data and Analytics Platform (RDCA-DAP®).

RDCA-DAP provides a centralized and standardized infrastructure to support and accelerate rare disease characterization targeted to accelerate clinical drug development. Additionally, the platform advances best practices to support the rigorous conduct of 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.



“We are excited to collaborate with Sanford Research, integrating the invaluable patient data they collected to help drive research for rare mitochondrial disorders including Leigh syndrome,” said Alexandre Bétourné, Ph.D., Pharm.D., Executive Director, RDCA-DAP. “This partnership demonstrates our shared commitment towards eliminating information silos in the field of rare mitochondrial disorders and an important milestone achieved through our collaboration with the Cure Mito Foundation.”

“Data sharing is critical for being able to help patients with the urgency they deserve. When we launched the Leigh syndrome patient registry, our vision was not only to offer hope for the future but to provide value to our community all along,” said Sophia Zilber, Board Member, Patient Registry Director, Cure MITO.

“Indeed, in less than two years, the data we have collected has been presented at conferences around the world, shared with researchers and industry partners, and utilized to contact potential study participants numerous times. We are thrilled to expand this progress by contributing our data to RDCA-DAP and are so grateful to both CoRDS and C-Path for their support and partnership.”

Since its inception, CoRDS has dedicated itself to coordinating the advancement of research into more than 10,000 rare diseases, working with patient advocacy groups, individuals, and researchers. The registry captures health information from diagnosed and undiagnosed patients, unaffected carriers, and at-risk patients. This valuable database connects researchers and patients and alerts participants of emerging clinical trials.

“We are excited to join forces with C-Path and contribute our registry data to RDCA-DAP,” said David Pearce, Ph.D., President of Sanford Research. “This collaboration will certainly advance our common goal — to accelerate research and treatment options for patients with rare diseases.”

Organizations interested in contributing data to RDCA-DAP can visit c-path.org/rdca-dap or email rdcadap@c-path.org. The platform is now OPEN and accepting applications for use; visit portal.rdca.c-path.org to apply and learn more.



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 and [C-Path in Europe](#) is headquartered in Amsterdam, Netherlands with additional staff in multiple other locations. For more information, visit c-path.org.

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