

Sanford Health Rare Disease Data Registry and C-Path's RDCA-DAP Enter into a Master Data Contribution Agreement to Aggregate Rare Disease Data

TUCSON, Ariz., October 16, 2024 – Critical Path Institute (C-Path) is pleased to announce the expansion of our partnership with the **Coordination of Rare Diseases at Sanford Research** (CoRDS). CoRDS entered into a master contribution agreement with C-Path's Rare Disease Cures Accelerator-Data and Analytics Platform (RDCA-DAP®), signaling a strong commitment to rare disease data sharing. Along with the agreement, C-Path shared that CoRDS has now contributed de-identified data on Malan syndrome (DEE), VCP disease (multisystem including myopathy with Paget and FTD), and Myhre syndrome (genetic, developmental) from its international patient registry to RDCA-DAP.

This follows a previous contribution of mitochondrial disorders data by CoRDS in [July 2023](#).

RDCA-DAP offers a centralized, standardized infrastructure designed to support and accelerate the characterization of rare diseases, aiding clinical development. The platform advances best practices for conducting rigorous natural history studies, adhering to high data quality standards essential for clinical trial design and regulatory review. It includes an integrated database and analytics hub for aggregating and efficiently interrogating rare disease data from diverse sources.

“We are excited to strengthen our collaboration with Sanford Research, integrating more of their invaluable data to help drive the approval of treatments for rare disorders including Malan, VCP and Myhre syndromes,” said Alexandre Bétourné, PhD, PharmD, Executive Director, RDCA-DAP. “This partnership signifies a unified stride towards eliminating information silos in the field of rare diseases and an important milestone achieved through our continued collaboration.”



“The purpose of the CoRDS Registry is to put information from the patient’s story into the hands of researchers to glean insights and advance therapeutic development. CoRDS is proud to work with C-Path on the initiative to continue making data accessible for researchers, industry, and the communities we all serve,” said Benjamin Forred, Sanford Health Director of Translational Research

and The CoRDS Registry.

Sanford and C-Path also collaborate within the International Rare Diseases Research Consortium (IRDiRC), enabling researchers worldwide to gain deeper insights into these diseases and expedite the development of new treatments.

Data sharing is critical for providing urgent help to patients. With the addition of these three datasets from CoRDS, the RDCA-DAP program can further accelerate research and treatment options for patients with rare diseases.

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.

Organizations interested in contributing data to RDCA-DAP can visit c-path.org/rdca-dap or email rdcadap@c-path.org. The platform is 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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