

Upcoming Rare Disease Workshop Focuses on the Importance of Data Sharing in Drug Development

C-Path, NORD and FDA to host annual workshop September 13-14 to highlight the impact of their innovative data and analytics platform on rare disease drug development



TUCSON, Ariz. and WASHINGTON, DC, August 25, 2022 — The Rare Disease Cures Accelerator-Data and Analytics Platform initiative ([RDCA-DAP®](#)) will host its in-person annual workshop on September 13 and 14 at the Westin [Crystal City](#). RDCA-DAP is funded by the US Food and Drug Administration (FDA), with the goal of transforming rare disease data into solutions to accelerate the development of therapies across rare diseases.



2022 RDCA-DAP Workshop

Sept. 13 - 14, 2022

Westin Crystal City
Reagan National Airport



REGISTRATION IS OPEN | <https://bit.ly/2022RDCA-DAPWorkshop>

The 1.5-day workshop will include a keynote address by Theresa Mullin, Ph.D., Associate Director for Strategic Initiatives, FDA, Center for Drug Evaluation and Research (CDER), and feature other key speakers and panelists from FDA, industry, academia and patient representatives. Included on the agenda are case studies shared by users of the platform, sessions covering critical topics on the impact of RDCA-DAP on accelerating drug development for rare diseases, as well as active discussions around data privacy and standards, and much more. A key objective of the workshop is to continue to energize the rare disease community to lead the way in actionable data sharing to accelerate medical product development for patients in need.

RDCA-DAP was created through a partnership between [Critical Path Institute](#) (C-Path), the [National Organization for Rare Disorders](#) (NORD®) and the [FDA](#), and has grown to include collaborations between a variety of stakeholders throughout the rare disease community. The platform serves as a centralized and standardized infrastructure to host and share data, to support and accelerate rare disease innovation.

Attendees of the in-person workshop will have the opportunity to explore:

- The impact of RDCA-DAP on drug development in rare diseases to date and envisioned impact for the future.
- Perspectives from patients, regulators, and industry on current and future impact.
- RDCA-DAP's unique support of multiple use cases across rare diseases.
- The role the rare disease community and patient advocacy groups can play in generating actionable solutions to accelerate drug development.

This is the fourth annual meeting for RDCA-DAP, and the first time the event will be held in person since the program's launch in 2019. Registration for the annual workshop is limited, so [reserve a spot today](#).

Registration is free and open to all rare disease community members and stakeholders, including members of the press. View the current agenda [here](#).

[REGISTER NOW!](#)

To request access to RDCA-DAP, [apply directly on the platform](#). To submit critical rare disease data, contact the project team at rdcadap@c-path.org or visit [the website](#).



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 dozens of pharmaceutical and biotech companies. C-Path U.S. is headquartered in Tucson, Arizona and C-Path, Ltd. EU is headquartered in Dublin, Ireland, with additional staff in multiple other locations. For more information, visit c-path.org and c-path.eu.

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About National Organization for Rare Disorders

The National Organization for Rare Disorders (NORD) is the leading independent advocacy organization representing all patients and families affected by rare diseases in the United States. NORD began as a small group of patient advocates that formed a coalition to unify and mobilize support to pass the Orphan Drug Act of 1983. Since then, the organization has led the way in voicing the needs of the rare disease community, driving supportive policies, furthering education, advancing medical research, and providing patient and family services for those who need them most. Together with over 300 disease-specific member organizations, more than 17,000 Rare Action Network advocates across all 50 states, and national and global partners, NORD delivers on its mission to improve the lives of those impacted by rare diseases. Visit rarediseases.org.

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