C-Path's RDCA-DAP Announces Strategic Partnership with Vivli to Enhance Clinical Trials Data Sharing for Rare Diseases

Vivli's Clinical Trials Data Platform and RDCA-DAP Will Make Data More Widely Accessible by Having Specific Data Sets Available on Both Platforms

TUCSON, Ariz., August 20, 2024 — Critical Path Institute (C-Path), the preeminent nonprofit leader in public-private partnerships to accelerate drug development, today announced a strategic data sharing partnership with Vivli, the independent, nonprofit organization committed to the advancement of global clinical trials data sharing. This collaboration signifies an important development in how C-Path's Rare Disease Cures Accelerator Data and Analytics Platform (RDCA-DAP®) and Vivli work to break silos in data sharing.

The first data sets, a phase II clinical trial in progressive supranuclear palsy (PASSPORT trial, NCT03068468) and two datasets in choroideremia, including a phase III clinical trial (STAR trial, NCT03507686) and a natural history study (NIGHT study, NCT03359551), all from Biogen, will be discoverable and shareable on RDCA-DAP. The harmonized dataset will also be discoverable on Vivli with access managed by RDCA-DAP.

RDCA-DAP, jointly established by C-Path and the National Organization for Rare Disorders with support from the FDA, aims to accelerate the development of treatments for rare diseases through enhanced data sharing and collaboration among key stakeholders, including academic researchers, industry leaders, healthcare organizations, and patient advocacy groups.

"Vivli and RDCA-DAP share a common vision in the urgency to share rare disease data as widely and broadly as possible and we both adhere to the FAIR principles of data sharing," remarked Alexandre Bétourné, Ph.D., Pharm.D., Executive Director for RDCA-DAP at C-Path. "We are thrilled to announce that Vivli, RDCA-DAP and Biogen collaborated to integrate a Progressive Supranuclear Palsy clinical trial dataset into both partnering platforms, as well as two datasets in choroideremia, our first data in rare eye disorders."

"The sharing of data between our platform and RDCA-DAP effectively enhances the findability of data for broader access by scientists worldwide," said Julie Wood, Vivli COO. "Interoperability between data platforms is key to breaking silos in data sharing and we hope this trailblazing effort serves as a model for other initiatives."

Janet Krause, Associate Director of Data Governance at Biogen, praised the partnership, "It is a privilege to contribute the first rare disease datasets. These datasets can now be analyzed on both Vivli and RDCA-DAP

secure environments, to advance science and improve public health."

"We are beyond excited here at Choroideremia Research Foundation (CRF) by the sharing of this valuable depersonalized data from these Biogen studies to RDCA-DAP. Choroideremia (CHM) is a rare inherited disorder that causes progressive vision loss and ultimately leads to complete blindness," said H. Eric Hartman, CRF Director of Advocacy. "This data set shared by BIOGEN includes a 2-year natural history study to characterize the progression of the disease. We are also extremely grateful to all of the CHM participants in these studies. In our view, making these studies available to the platform users is critical as it will become a vital tool in advancing current CHM research both now and in novel approaches in the future. We applaud this impressive collaborative effort by RDCA-DAP and Vivli with BIOGEN in establishing a global secure platform for CHM data sharing."