C-Path and Pulse Infoframe Establish Patient-Centered Data Harmonization Partnership to Accelerate Collaborative Research in Rare Disease

LONDON, Canada and **TUCSON**, Ariz., U.S., September 30, 2021, 2021 — Critical Path Institute (C-Path) and Pulse Infoframe announced today their collaboration to advance technologies and tools to further rare disease research and drug development. In addition, both organizations will support the creation of more streamlined and transparent informed consent processes and best practices for the development of global unique identifiers, data standards and data dictionaries.

Dr. Femida Gwadry-Sridhar founded Pulse Infoframe in 2011 to begin removing the data barriers that hinder rare disease research. The company has since developed patient registries for many rare diseases, most recently Alport Syndrome, a rare kidney disease. Removing these barriers requires implementing data standards and transparent patient consent practices, so data can be ethically and legally shared. Working closely with KOLs across clinical, academic and advocacy backgrounds, Pulse Infoframe brings these specialists together as part of a governance structure for each of its registries to provide guidance and transparency with stakeholders.

C-Path aims to accelerate the pace and reduce the costs of medical product development through the creation of new data, measurement and methods standards that aid in the scientific evaluation of the efficacy and safety of new therapies.

An individual rare disease can often not produce enough data for researchers to develop treatments. Through this collaboration, Pulse Infoframe and C-Path can accelerate the development of treatments for rare diseases by sharing their data and advancing new models, tools and data standards based on that data. The two organizations will identify opportunities to combine Pulse Infoframe's ambispective data with retrospective data in C-Path's Rare Disease Cures Accelerator-Data and Analytics Platform (RDCA-DAP®), an FDA-funded initiative to support rare disease drug development.

"Siloed data has always been a hindrance to rare disease research," says Pulse Infoframe founder and Chief Executive Officer Dr. Femida Gwadry-Sridhar. "The tools used to collect data must be designed so that the data are standardized and therefore meaningful. This also means they will be useful in the future. Our partnership with C-Path will expand in these areas and accelerate research in the rare disease space."

Both Pulse Infoframe and C-Path use a centralized infrastructure that allows for research across diseases. Instead of researchers being limited to symptoms of a single disease, for example, they can study a symptom that is common to several diseases, thereby increasing the amount of data available to them.

"Working jointly with Pulse Infoframe, we can lead the conversation on data standards and drive the rare disease ecosystem to adopt best practices on data collection and management to the benefit of all," said Jeff Barrett, Ph.D., F.C.P., C-Path Senior Vice President and RDCA-DAP Lead. "RDCA-DAP and Pulse Infoframe have been able to gather distinct datasets in common rare diseases of interest.

The partnership between C-Path and Pulse Infoframe, and its combined data pool, will benefit the rare disease ecosystem, including patients, advocacy, researchers and pharma/biotech by supporting the development of the following:

- Open data science strategies that support disease progression models and drug development tools informed by this combined data;
- more sophisticated AI/ML-based approaches and methodologies to advance the knowledge in rare disease biology understanding based on analyses of these combined data;
- data standards (GUID, CDM, data dictionaries) and their adoption by the industry; and more streamlined and transparent informed consent processes.

“We have a unique opportunity to leverage each platform’s data content, technical knowledge and quantitative medicine expertise to accelerate the development of solutions and drug development tools for rare disorders. There is a tremendous potential from collaborating with Pulse Infoframe,” said Alexandre Bétourné, Ph.D. Pharm.D., RDCA-DAP Scientific Director.

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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. Learn more at c-path.org and c-path.eu.

About Pulse Infoframe
Pulse Infoframe is a real-world evidence generation, health informatics and insights company that provides a technology and services platform designed to extract, curate, analyze and disseminate evidence-based conclusions that improve the quality of people’s lives. Pulse Infoframe provides a full solution for registries, natural history studies and a range of other observational and regulatory grade studies. With provider relationships for patient access, Pulse Infoframe ensures that insights, evidence and publication results are disseminated across the ecosystem, including advocacy organizations, key opinion leaders, researchers and sponsors. Learn more at pulseinfoframe.com.

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