C-Path and Sturge-Weber Foundation Announce Data Sharing Agreement to Support Treatment Development for Sturge-Weber Syndrome

TUCSON, Ariz., October 20, 2022 — Critical Path Institute (C-Path) and the Sturge-Weber Foundation today announced a joint collaboration to incorporate patient data for Sturge-Weber syndrome (SWS) into C-Path's Rare Disease Cures Accelerator-Data and Analytics Platform (RDCA-DAP®).

SWS is a highly variable, rare vascular disorder, including congenital facial marks, abnormal blood vessels in the brain, and/or eye abnormalities such as glaucoma. The integration of these patient-level data enables greater analysis from a larger number of patients, allowing for a broader and more comprehensive understanding of the natural disease progression in SWS, while also helping to eliminate data silos and ensuring the data is utilized to its fullest extent.

C-Path's RDCA-DAP® provides a centralized and standardized infrastructure to support and accelerate rare disease characterization targeted for clinical development. Additionally, the platform includes a framework that supports 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 grateful to the Sturge-Weber Foundation for allowing us to partner with them to help advance SWS research," said Alexandre Bétourné. "Integrating the foundation's patient data into RDCA-DAP will help accelerate understanding of how the disease progresses and facilitate the development of innovative clinical trial designs and better patient outcomes. It may also help inform work for other diseases as our platform continues to aggregate data from patients with rare neurological disorders."

About Sturge-Weber Foundation
Founded in 1987 by Kirk and Karen Ball as a non-profit organization after their daughter, Kaelin, was diagnosed with Sturge-Weber Syndrome at birth, the SWF's mission is to improve the quality of life and care for people with Sturge-Weber syndrome through collaborative education, advocacy, research and friendly support. In 1992, the mission was expanded to also support and serve individuals with Klippel-Trenaunay syndrome and isolated Port-Wine Stain birthmark conditions.

The Vision of the Sturge-Weber Foundation (https://sturge-weber.org) is that in all areas of life (public, professional, personal) the following goals will be achievable for our members:

Awareness, when the public will be able to see past the disability to the person.
Empowerment, when families and individuals will be able to obtain the medical care, employment, education, respect and personal achievement they seek.
Research when the pace of discovery will not be hampered by lack of resources and will lead continually toward a cure and advances in treatment.

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, C-Path in Europe is headquartered in Amsterdam, Netherlands and C-Path Ltd. operates from Dublin, Ireland with additional staff in multiple other locations. For more information, visit c-path.org.

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