CRITICAL PATH INSTITUTE

PBC Ireland Partners with C-Path's Rare Disease Data Platform, Advancing Research Efforts for Primary Biliary Cholangitis

Integration of Irish PBC Patient Registry Data into RDCA-DAP Brings Patient-Centered Insights to Rare Liver Disease Research

TUCSON, Ariz., March 17, 2026 — In a significant step to enhance research efforts for Primary Biliary Cholangitis (PBC), Critical Path Institute® (C-Path) and PBC Ireland are pleased to announce a new data sharing agreement. This collaboration integrates de-identified data from the PBC Ireland Patient Registry into C-Path's Rare Disease Cures Accelerator–Data and Analytics Platform (RDCA-DAP®), marking an important step forward in advancing understanding and treatment of this autoimmune liver disease.

PBC Ireland, a national patient-led organisation advancing research, advocacy, and community engagement in PBC, is at the forefront of developing innovative, patient-focused research infrastructure in Ireland. Through its IRB-approved, longitudinal patient registry, PBC Ireland brings together one of the most comprehensive real-world datasets on PBC in Ireland, offering new insights into disease burden, treatment response, and the lived experience of people with PBC. This collaboration strengthens global efforts to better understand PBC and accelerate evidence generation for improved care.

PBC IRELAND

"The inclusion of PBC Ireland registry data within RDCA-DAP represents a significant advance for PBC research. It highlights the growing role of patient-led registries in accelerating rare disease innovation and underscores the value of high-quality real-world data in shaping future therapeutic development," said Heidi Grabenstatter, Ph.D., Scientific Director for RDCA-DAP at C-Path. "The integration of their patient registry data into RDCA-DAP strengthens our research capabilities and brings us closer to accelerating evidence generation and advancing therapeutic innovation for individuals affected by PBC."

Gerry Nesbitt, MBA, Founder of PBC Ireland, also shared his perspective, "Our partnership with C-Path and the inclusion of the PBC Ireland Patient Registry data into RDCA-DAP reflects our commitment to ensuring that the lived experience of people with PBC directly informs research and therapeutic development. As a patient-led initiative, this collaboration represents an important step in elevating real-world patient data onto a global platform. It strengthens our collective efforts to accelerate evidence generation and ultimately improve treatment and care for everyone affected by PBC. We are deeply grateful to the PBC patients who contributed their data and made this milestone possible."

RDCA-DAP, a joint initiative by C-Path and the National Organization for Rare Disorders with support from the U.S. Food and Drug Administration, offers a unique platform promoting cooperation among various stakeholders, including academic institutions, industry leaders, healthcare organizations, and patient advocacy groups. It accelerates the development of treatments for rare diseases through data sharing, analysis, and collaboration.

The contribution of PBC Ireland Patient Registry data to RDCA-DAP marks a significant step forward in research specific to primary biliary cholangitis. It demonstrates the power of patient-led collaboration in advancing innovative discoveries, not only for PBC but for the rare disease community more broadly. It underscores the vital role of PBC Ireland in advocating for liver research and highlights the potential of shared, high-quality real-world data to accelerate progress toward improved treatments and, ultimately, better outcomes for people living with PBC.

Organizations interested in contributing to RDCA-DAP can learn more and reach out at 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 for further information.

About Critical Path Institute
Critical Path Institute® (C-Path) is an independent, nonprofit established in 2005 as a public-private partnership, in response to the FDA's Critical Path Initiative. C-Path's mission is to lead collaborations that advance better treatments for people worldwide. Globally recognized as a pioneer in accelerating drug development, C-Path has established numerous international consortia, programs and initiatives that currently include more than 1,600 scientists and representatives from government and regulatory agencies, academia, patient organizations, disease foundations and pharmaceutical and biotech companies. With dedicated team members located throughout the world, C-Path's global headquarters is located in Tucson, Arizona and C-Path's Europe subsidiary is headquartered in Amsterdam, Netherlands. For more information, visit c-path.org .

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About PBC Ireland
The mission of PBC Ireland is to advance research, build community, and advocate for improved care and outcomes for people living with Primary Biliary Cholangitis in Ireland. Founded by patients, PBC Ireland is a patient-led organisation committed to strengthening the patient voice in research, policy, and clinical practice. Through its IRB-approved, longitudinal patient registry and national advocacy initiatives, PBC Ireland works to generate meaningful real-world evidence and support people affected by PBC across the country.

For more information, please contact Gerry Nesbitt, PBC Ireland at gerry@pbcireland.org or visit https://www.pbcireland.org

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