CRITICAL PATH INSTITUTE

Advancing Hope in Progressive Supranuclear Palsy: Collaboration, Data, and Innovation During PSP Awareness Month

Each May, Progressive Supranuclear Palsy (PSP) Awareness Month shines a light on a devastating neurodegenerative disease that remains widely underrecognized, despite its profound impact on patients, families, and caregivers. PSP is a rare brain disorder that affects movement, balance, speech, swallowing, vision, and cognition. Over time, people living with PSP often experience increased difficulties with mobility and daily function, while facing a significant lack of effective treatment options.

For the PSP community, May is more than a time for recognition—it is a call to action to accelerate research, improve clinical understanding, and advance the development of therapies that can meaningfully change patients' lives.

At Critical Path Institute® (C-Path), that mission is central to our work. And we take pride in it every day.

In January 2024, C-Path launched the Progressive Supranuclear Palsy Task Force through its Rare Disease Cures Accelerator–Data and Analytics Platform (RDCA-DAP®). The initiative was created to address the urgent need for better tools, stronger collaboration, and more efficient drug development pathways for PSP.

This growing collaboration brings together leading organizations across the PSP ecosystem, including CurePSP, Rainwater Charitable Foundation, AFTD, Novartis, Arvinas and academic experts, all united by a shared goal: accelerating drug development and improving lives for people living with PSP.

Since its launch, the PSP Task Force has already achieved several important milestones. The initiative has delivered a robust natural history and clinical trial database and opened data access to multiple researchers, helping them better understand how PSP progresses over time and inform their clinical trial design activities, including endpoints selection. In addition, the initiative is leveraging the database to support analytics of clinical endpoints and developing Disease Progression Models that will support a future Drug Development Tool designed to support more informed data-driven decision-making in therapeutic development.

These advances are critical in a disease area where small patient populations, limited longitudinal data, and clinical complexity have historically slowed progress.

Through RDCA-DAP, C-Path enables the integration and analysis of patient-level data from diverse sources, helping stakeholders identify critical gaps in PSP research while advancing biomarkers and clinical outcome assessments. By fostering collaboration amongst industry, academia, regulators, and patient advocacy organizations, the platform creates a shared scientific foundation that can reduce duplication, improve trial design, and accelerate the development of new treatments.

Equally important is the fact that these efforts ensure the patient voice remains central throughout the research and drug development process. For rare neurodegenerative diseases like PSP, collaboration amongst industry and patient advocates, as well as data sharing, are essential efforts needed to overcome longstanding hurdles. RDCA-DAP provides the infrastructure and scientific framework needed to transform fragmented data into actionable insights that can ultimately improve clinical development and patient outcomes.

This PSP Awareness Month, C-Path recognizes the resilience of the PSP community and reaffirms its commitment to advancing innovative, collaborative solutions that bring hope closer to reality for those living with this devastating disease.

To learn more about C-Path's PSP Task Force and ongoing efforts through RDCA-DAP, click here.