Winsights Establishes Group of Leading Scientific and Clinical Advisors to Advance Research Through Patient Insights

Initiative Debuts with HSP Study and Advisors from Harvard Medical School, University of Michigan, Cornell Tech, Texas A&M, and former FDA leadership

BOSTON, MA, UNITED STATES, July 14, 2026 /EINPresswire.com/ -- Winsights, a patient-powered healthcare ecosystem advancing rare disease research through real-world patient and caregiver insights, today announced the formation of its group of scientific and clinical experts and the launch of its first observational research initiative focused on hereditary spastic paraplegia (HSP), including AP-4-HSP (SPG47).

> Patients and caregivers recognize important patterns before they become visible in traditional healthcare. Winsights transforms those experiences into insights that accelerate rare disease research."
>
> *Kasey Walsh, Founder and CEO of Winsights*

Rare disease research is often limited by fragmented patient data and an incomplete understanding of how conditions affect daily life. Winsights was created to address that challenge by combining community engagement with structured research participation into a single ecosystem. Through the collection of patient and caregiver experiences, the platform is designed to generate real-world evidence that can help researchers better understand disease burden, inform future studies, strengthen clinical trial readiness, and support therapeutic development efforts.

To translate those insights into meaningful scientific and clinical impact, Winsights has assembled a multidisciplinary group composed of leaders in rare disease research, clinical care, real-world evidence, therapeutic development, and patient-centered innovation. The advisors will help guide Winsights as it develops patient-centered approaches to evidence generation, community engagement, and future research initiatives designed to improve outcomes for individuals living with rare diseases.

The inaugural advisory group includes:

- Saurabh Biswas, Ph.D. – Professor of Practice in Biomedical Engineering at Texas A&M University; Executive Director of Technology Transition, Texas A&M - Engineering; Co-founder of Pleozyme, Corinnova, and Shape Memory Medical.
- Craig Blackstone, M.D., Ph.D. – Julieanne Dorn Professor of Neurology, Harvard Medical School & Scientific Director, Mass General Brigham Neuroscience Institute
- Jessica Duis, M.D., M.S. – Board-certified geneticist and rare disease physician; Founder of many Centers of Excellence across neurogenetic conditions, Founder of RareDiseaseDoc, Pharma Executive
- John K. Fink, M.D. – Director, Neurogenetic Disorders Clinic and Professor, Department of Neurology, University of Michigan; internationally recognized expert in hereditary spastic paraplegia and neurogenetic disorders
- Thomas Kent, M.D. – Neurology physician-scientist, Texas A&M Health Science Center-Houston, Director of the Gulf Coast Consortium Rare Disease Network; co-founder of Pleozyme, Inc.
- Tamar Lasky, Ph.D., FISPE – Former Senior Advisor on Real-World Evidence, U.S. Food and Drug Administration
- Thijs Roumen, Ph.D. – Assistant Professor of Information Science, Cornell Tech; Executive Board Member of the Cornell Initiative on Accessible Technology and AI
- Richard Novak, Ph.D. – Founding CEO of Unravel Biosciences; former Lead Engineer at the Harvard Wyss Institute

“Most knowledge of a medical condition, including its symptoms, natural history, and response to treatment, stems from information collected by health professionals and published literature,” said Dr. John Fink, Director, Neurogenetic Disorders Clinic, University of Michigan. “Missing from this perspective is the patient's self-reported experience. There has been no systematic mechanism for collecting information directly from affected individuals, their family members, and caregivers. Until Winsights."

Additionally, Winsights is launching an observational research initiative led by Dr. Jessica Duis to better understand hereditary spastic paraplegia through structured patient and caregiver experiences. The study will examine disease burden, symptom progression, quality of life, and caregiver experiences. AP-4-HSP was selected as Winsights’ inaugural research focus because it represents both the community that inspired the platform's creation and an opportunity to demonstrate how patient-generated insights can advance research across rare diseases.

“I am deeply humbled to lead research efforts at Winsights and help bring Kasey Walsh’s vision to life,” said Dr. Jessica Duis, board-certified geneticist and rare disease physician. “By elevating patient and caregiver voices, we can build a connected community, advance research, and strengthen clinical trial readiness across diverse populations.”

Founded by rare disease advocate Kasey Walsh, a caregiver and mother of a daughter living with a rare genetic disorder, Winsights was established to address persistent challenges facing rare disease communities, including delayed diagnoses, limited natural history data, and gaps in understanding how disease impacts daily life. Winsights plans to expand its research initiatives

into additional rare disease communities while partnering with advocacy organizations, clinicians, researchers, and industry to accelerate patient-centered evidence generation.

For more information, visit: Winsights.life.

About Winsights
Winsights is a patient-powered healthcare ecosystem that turns lived experience into real-world evidence to advance rare disease research. By integrating community engagement with structured data collection, Winsights helps researchers, clinicians, advocacy organizations, and industry partners better understand disease burden, accelerate therapeutic development, and ensure that the patient voice informs every stage of research.

Kozak Reitano Communications Group
Winsights.life LLC
diana@krcommsgroup.com
