Kabuki Syndrome Foundation Launches Kabuki INSIGHTS to Support Future Treatment Development

Research platform designed to help researchers better understand Kabuki syndrome, strengthen clinical trial readiness, and inform future treatment development.



Introducing Kabuki INSIGHTS

NORTHBROOK, IL, UNITED STATES, October 1, 2026 /EINPresswire.com/ -- Today, the Kabuki Syndrome Foundation (KSF) announced the launch of Kabuki INSIGHTS (INtegrated registry Study for Insights into Genetics, Health & Therapeutic Strategies in Kabuki syndrome). Kabuki INSIGHTS is a patient-powered research platform designed to support research and treatment development for Kabuki syndrome. The registry collects information through online surveys and, optionally, electronic health records.

Kabuki INSIGHTS is designed to generate the real-world evidence researchers need to better understand Kabuki syndrome, identify unmet needs, strengthen future clinical trials, and support future treatment development by bringing together the lived experiences of individuals and families with clinical information.

“Kabuki INSIGHTS is rooted in the belief that every family’s experience can help move our entire community forward. By bringing together information from people with Kabuki syndrome around the world, we can build a more complete picture of the syndrome and ensure that families everywhere have a meaningful role in shaping the future of research and care.” Patrick Dunbar, Executive Director, Kabuki Syndrome Foundation

Since its founding in 2018, KSF has evolved from a research funder into the global hub for Kabuki syndrome research, collaboration, and community. The organization has awarded 28 research grants in seven countries, investing more than $2.8 million in treatment research while building a collaborative network of more than 260 clinicians, researchers, and industry professionals dedicated to improving outcomes for people with Kabuki syndrome.

By creating a centralized platform where individuals and families can contribute their

experiences over time, KSF is helping build the research infrastructure needed to support scientific discovery, improve understanding of Kabuki syndrome, and prepare the community for future clinical trials and therapies.

“Researchers and regulatory agencies need robust, real-world data to understand how Kabuki syndrome affects individuals across the lifespan. Kabuki INSIGHTS is designed to help reveal patterns, identify unmet needs, and generate the evidence researchers need to design stronger studies and support progress toward future treatments.” Dr. Clara Tang, Chief Scientific Officer, Kabuki Syndrome Foundation

Unlike information collected during a single research study, Kabuki INSIGHTS is designed to grow alongside the Kabuki syndrome community. Because data is collected over time, the registry aims to build a picture of the condition across childhood, adolescence, and adulthood - knowledge that can help shape future research priorities and treatment development.

“Research registries help healthcare providers and researchers learn from a large community of individuals and families living with Kabuki syndrome. By bringing together real-world experiences and medical information over time, we can build a fuller picture of the condition and work toward improved care and future treatments.” Dr. Margaret P. Adam, Clinical Geneticist at Seattle Children’s Hospital, University of Washington, KSF Medical & Scientific Advisory Board, and Kabuki INSIGHTS Steering Committee Member

Researchers also see Kabuki INSIGHTS as an important step toward strengthening treatment development for Kabuki syndrome.

“Well-governed patient registries are essential for generating scientifically valid and objective real-world evidence in rare disease. Kabuki INSIGHTS is designed to create a durable, research-ready dataset that can support future scientific and therapeutic research.” Jeff Trotter, MBA, Principal, J Trotter Research & Consulting, KSF Industry Advisory Board, and Kabuki INSIGHTS Steering Committee member

Kabuki INSIGHTS is guided by a Steering Committee convened by the Kabuki Syndrome Foundation (KSF). The Steering Committee brings together scientific, clinical, community, and industry expertise to help ensure the registry is well designed, responsibly governed, and useful for future research.
Kabuki INSIGHTS opened to enrollment on October 1, 2026. More information is available at the Kabuki Syndrome Foundation's website.

About the Kabuki Syndrome Foundation

The Kabuki Syndrome Foundation drives research and treatment development, while fostering a global community of families, clinicians, and researchers to improve the lives of people with Kabuki syndrome. Since 2018, KSF has invested more than $2.8 million directly into research,

supported investigators in seven countries, and built an international collaborative network dedicated to accelerating scientific discovery and advancing future treatments.

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