About Us

When we began in 2017, fewer than 100 individuals were known to have KAT6 syndrome caused by KAT6A and KAT6B gene variants. Today, we have more than 550 individuals counted in our registry. This remarkable progress reflects greater awareness, improved diagnosis, and the strength of our connected global community.

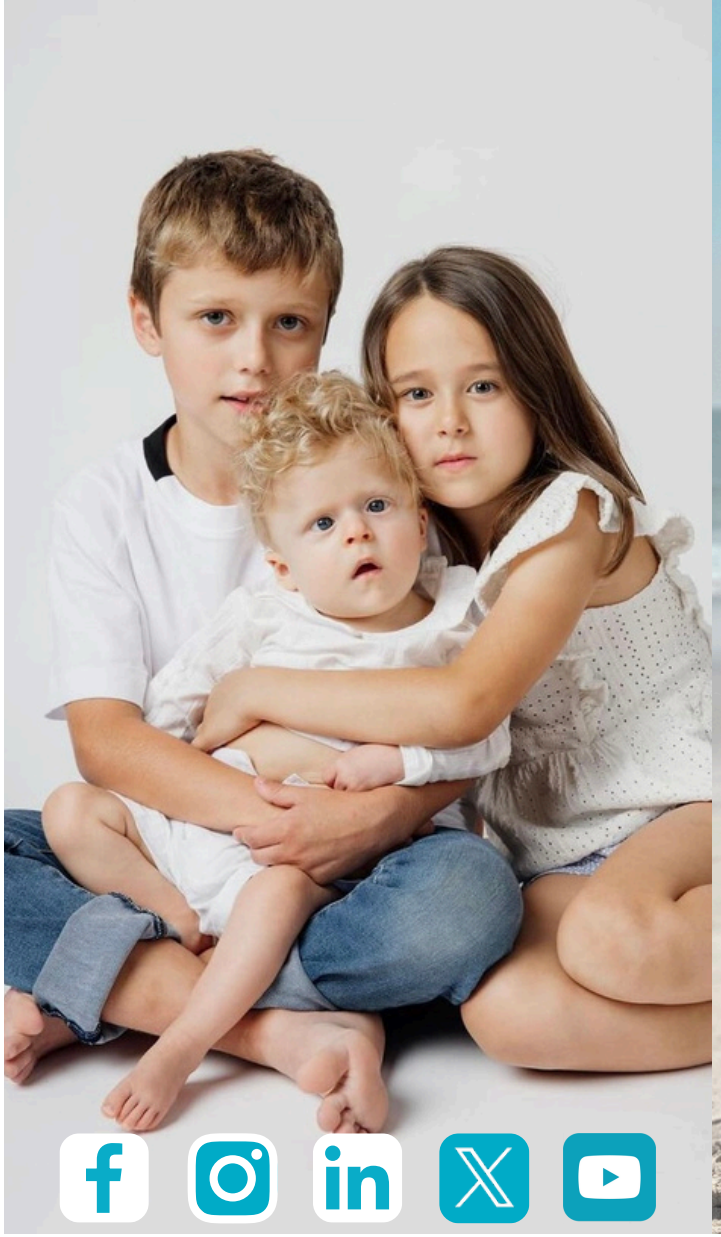
We are the only 501(c)(3) nonprofit organization founded to support the international KAT6 community.

Our Mission

The KAT6 Foundation supports individuals and their families who are living with KAT6A and KAT6B syndromes around the world.

We **advance scientific research** aimed at developing treatments, and **spread awareness** of KAT6 syndromes so they can be more easily identified, treated, and studied.

"Alone we can do so little; together we can do so much."



Join Us

KAT6 Foundation

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support@kat6.org

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KAT6.ORG

KAT6 Foundation

Driving Research

WE PROUDLY FUND AND SUPPORT INTERNATIONAL RESEARCH

KAT6A/KAT6B PATIENT REGISTRY

Launched in 2019 in partnership with the National Organization for Rare Disorders (NORD), the KAT6A/KAT6B Patient Registry is the first long-term study of KAT6 syndrome. The registry collects family-reported data to advance research, deepen understanding of KAT6, and share meaningful insights with our community.

iPSC BANK AT BOSTON UNIVERSITY

In 2022, the KAT6 Foundation, together with the Center for Regenerative Medicine (CReM) and The Serrano Lab at Boston University, established the first patient-derived induced pluripotent stem cell (iPSC) bank for KAT6A and KAT6B. This resource was created to give researchers access to high-quality cell lines that reflect the unique genetics of individuals with KAT6 syndromes.

FUNDING NEW RESEARCH

In 2026, we proudly support eight new studies advancing our understanding of KAT6 These projects address disease mechanisms, model development, potential therapies, and biomarkers—laying critical groundwork for clinical trials.

Supporting Families

EMPOWERED GRANT PROGRAM

- Provides funding for the purchase of assistive equipment, devices, technology, and a variety of therapies.

ADVOCACY TEAM

- Helps caregivers navigate the educational and medical systems to make informed decisions and obtain optimal services and care for their child.

KAT6 CONFERENCE

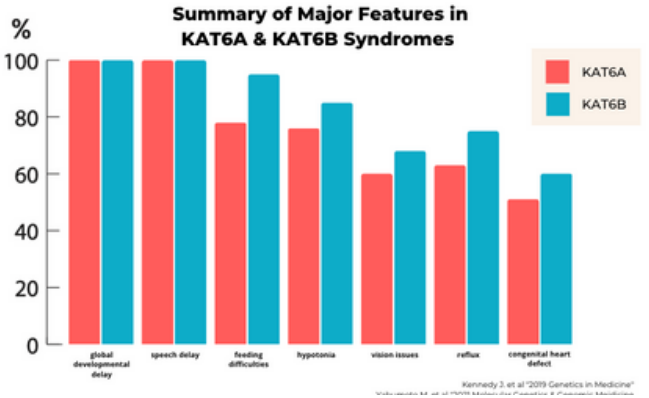
- Enables open dialogue between families, clinicians, and researchers.
- Provides a platform for the KAT6 community to expand its network.

BRINGING FAMILIES TOGETHER

- Facebook support group
- Online webinars
- Awareness events

Features of KAT6

Each person with KAT6 syndrome has a different variant along the KAT6A or KAT6B gene, which leads to a wide range in symptoms and features.



DIAGNOSTIC TESTING OPTIONS FOR KAT6:

- **Whole Exome Sequencing (WES):** Analyzes coding regions where most disease-causing variants are found.
- **Whole Genome Sequencing (WGS):** Examines the entire genome for the most comprehensive results.
- **ID-NGS Panel:** A targeted panel including KAT6 variants; often faster and more likely to be covered by insurance as a first step.