KAT6 Foundation

IMPACT REPORT
JAN 2025 - JUNE 2026

RESEARCH ADVANCEMENTS

- Funded 8 active research projects focused on understanding KAT6 disorders and developing potential therapies.
- Expanded the KAT6 iPSC Biobank to 42 patient samples, providing researchers with critical tools for discovery.
- Advanced collaborations among leading researchers at Boston University, UCLA, Boston Children's Hospital, McGill University, Weill Cornell Medicine, Murdoch Children's Research Institute, and other centers working to improve outcomes for individuals with KAT6 disorders.
- The KAT6A/KAT6B Patient Registry now includes more than 560 participants worldwide, providing researchers with one of the largest sources of natural history data available for KAT6 disorders.

PATIENT & FAMILY SUPPORT

560+
registered

- Published the new KAT6 Caregiver Handbook in 19 languages, ensuring families around the world have access to trusted information regardless of where they live.
- Launched a newly redesigned website to improve access to trusted resources and educational materials
- Expanded our educational resource library with new materials for families and healthcare professionals, including the video When the Plans Change: A Simple Explanation of KAT6 and practical clinical resources on gastrointestinal issues in KAT6.
- Continued our Empowered Grants program, helping families access therapies, communication supports, adaptive equipment, and other critical needs. Since 2020, more than 130 grants have been awarded to families worldwide.

2025-2026 IMPACT REPORT

BUILDING CONNECTIONS

- In 2025, we welcomed more than 200 participants to our 6th International KAT6 Conference, bringing together families, researchers, clinicians, and therapists from around the world.
- KAT6 Connect, our inaugural family-focused event, will take place November 6-8 in Dallas, Texas. This new family-focused event is designed to strengthen connections, education, and support.
- Expanded opportunities for families to connect through virtual programs, social media communities, educational webinars, and peer-to-peer support networks.

RAISING AWARENESS

- Expanded partnerships with researchers, clinicians, advocacy organizations, and industry partners to increase awareness of KAT6 syndrome and advance opportunities for collaboration.
- Created a Welcome Video to help newly diagnosed families feel connected, informed, and supported from the very beginning of their journey.

LOOKING AHEAD

IIn the coming year, we look forward to sharing progress from our portfolio of eight funded research projects, expanding educational resources, growing participation in the patient registry, and bringing our global community together through KAT6 Connect 2026 and future scientific meetings.

Advancing Research. Empowering Families. Building Community.

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