

## Caregiver Checklist for KAT6 Syndromes



### MEDICAL FOLLOW UP

- Meet with your child's pediatrician or geneticist to review the diagnosis.
- Confirm which specialists to see and schedule initial appointments.
- Keep copies of reports, test results, imaging, and recommendations.



### EARLY INTERVENTION AND SCHOOL SERVICES

Ages 0–3:

- Request an Early Intervention evaluation.
- Track therapy recommendations and progress.

School age:

- Request a school-based evaluation.
- Set up an Individualized Education Plan (IEP) or the equivalent used in your country.



### REGISTER

- Join the KAT6A/KAT6B Patient Registry. [Register Here](#)
- Complete the KAT6 Community Survey. [Take Survey](#)



### CAREGIVER SUPPORT

- Join the KAT6 Support Group on Facebook to connect with others for shared experiences and advice. [Join Group](#)
- Watch the Foundation's welcome video for new families. [Watch Video](#)
- Lean on your friends and family—they can be a vital source of emotional support.



### ORGANIZE YOUR RECORDS

- Create a binder or digital folder for:
  - Medical summaries and evaluations
  - Therapy and school plans and reports
  - Specialist contact information
  - Appointment notes
  - Development logs



### STAY UPDATED

- Follow the KAT6 Foundation on [Facebook](#), [Instagram](#), [LinkedIn](#), [X](#), and [YouTube](#).



### RESEARCH OPPORTUNITIES

- Review current research studies and data collection projects at KAT6.org.
- Sign up to contribute to the KAT6 iPSC Bank. [Learn more.](#)
- Save any consent documents for your records.