KAT6 Clinic at Boston Children's Hospital

We are writing to let you know about a new multidisciplinary clinic for children and adults with genetically confirmed **KAT6A and KAT6B-related disorders**.

KAT6A/B-related disorders are rare genetic conditions that may affect many different organ systems requiring **coordinated, multidisciplinary holistic care**. Our clinic seeks to address these unmet needs through an integrated care model that is based on the latest knowledge about these conditions.

The sub-specialists we work with are highly experienced, empathetic, and talented physicians, although some may have limited experience with KAT6A/B-related disorders. As we grow our clinic, so will our experience and knowledge.

Depending on your needs, you may see a developmental pediatrician or neurologist, a speech and language therapist, a dietitian and/or gastroenterologist, a physiotherapist and occupational therapist, a psychologist (developmental and behavioral assessment) and any additional specialists (for example cardiology, ophthalmology, orthopedics, hematology, urology, kidney or dental services) as required.

If you are interested in an appointment in our KAT6 Clinic, please send an email to rarediseases@childrens.harvard.edu including the patient's age, condition, state/country of residence and expected timeframe for the visit. **You can expect a response within two business days that includes forms for you to fill out.** After reviewing all information, we will reach out with a list of recommended appointments with us and other sub-specialists as needed as well as any information relevant to insurance coverage. This may take up to two weeks. Clinic appointments are typically available within a month's notice. If you already have a doctor/team managing your care, joining the clinic will not replace them. We will work together with the local care team. For families traveling from out of state or internationally, our finance team is available to assist with insurance coverage and related financial questions.

At the visit you will meet several team members, ideally in the same location, you only need to tell your story once. If you are seen by other sub-specialists, all relevant information will be made available to them prior to the visit. We will typically review growth, development, feeding, heart, vision, hearing, sleep, behavior, and any other concerns, take a detailed past medical and family history, perform an in-depth physical exam and discuss any implications and/or recommendations for testing. The initial visit with us may take one to two hours depending on complexity, the visits with the sub-specialists will typically take one hour. We will try to coordinate multiple visits as best as we can.

You will receive a written summary and care plan ("action grid") after the visit. A copy will be sent to your family doctor and other specialists involved (with your permission). Follow-up will be scheduled as needed and you can always reach out to us with any questions through the Boston Children's Hospital patient portal.

If you have any questions, or need this letter in another language or format, please contact us at rarediseases@childrens.harvard.edu. We understand that living with a rare condition can be challenging, and we look forward to meeting you and supporting your family.

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