FOXG1 syndrome is a rare genetic neurodevelopmental disorder caused by changes in the FOXG1 gene. FOXG1 is important for early brain development, and when impaired causes cognitive and physical disabilities. Every person with FOXG1 syndrome is unique, but common symptoms include: developmental differences, feeding difficulties, epilepsy, and movement disorders. Typically, FOXG1 syndrome is not inherited from a parent and does not run in families.

Get Involved
Our foundation drives research and advocacy for the children and adults living with FOXG1 syndrome. We are committed to breakthrough discoveries and life-changing advances in research while supporting families.

Fundraise
We are raising money to fund cutting-edge research, including programs dedicated to gene therapies and clinical trial readiness. With your support, we can accelerate research to improve the lives of children and adults with FOXG1 syndrome.

Join Us
There are many ways you can join and contribute to our community.

To get started, create a dashboard for your child in our FOXG1 Patient Data Center. This is an important effort where both parents and clinicians come together to advance our path to a cure!
FOGX1 syndrome can manifest as a spectrum, where symptoms and severity vary between individuals. In most cases, features of FOXG1 syndrome appear early in life, and can evolve with age.

Neurological symptoms
- Microcephaly (small brain size)
- Cortical visual impairment (CVI)
- Epilepsy or seizures
- Movement disorders

Developmental symptoms
- Gross motor delays or disabilities (i.e. difficulty sitting independently)
- Fine motor delays or disabilities, (i.e. difficulty using hands purposefully)
- Speech and language delays or disabilities
- Challenges with daily living skills (i.e. dressing, eating, toilet training)
- Autism spectrum disorders (ASD)

Other symptoms
- Feeding difficulties
- Gastroesophageal reflux (GERD)
- Constipation
- Difficulty falling or staying asleep
- Crossed eyes (also called strabismus)

We are a community.

There is a growing community of families whose children have received a diagnosis of FOXG1 syndrome. To date, there are approximately 1000 individuals living with FOXG1 syndrome worldwide. We have been where you are. You have a FOXG1 family here to support you - you are not alone.

FOXG1 Management

There is no cure for FOXG1 syndrome, but supportive therapies are available to help manage symptoms. Depending on your child’s symptoms, these can include medications, nutritional support, surgeries, developmental therapies, and assistive devices (including augmentative and alternative communication strategies).

Your care team will come together to develop a treatment plan that is tailored to your child’s specific needs. This team may include experts from a variety of specialties, including: neurology, epilepsy, genetics, gastroenterology, ophthalmology or optometry, and developmental therapists.

Some children’s hospitals support multidisciplinary clinics to provide expert care to individuals with genetic disorders. Some examples include: Boston Children’s Hospital, Colorado Children’s Hospital, Children’s Hospital of Philadelphia.