## RESEARCH AND SUPPORT

IFF is working with Boston Children's Hospital Translational Neuroscience Center in Boston, Massachusetts on a research project. The goal of this project is to take tissue and blood samples from FOXG1 affected individuals, turn them into stem cells, and "push" those cells into neurons, called inducible pluripotent stem cells, or iPSCs. These cells will allow for drug testing in a dish, and the researchers will be able to see what medications may be able to interact directly with the brain cells.

FOXG1 Protein Representation



Thanks to the fundraising efforts of our FOXG1 families, in March of 2015, we secured the funds required to develop a FOXG1 mouse model. This mouse has been completed, and, as of January, 2017, two breeding pairs have been produced and the development of a colony has begun. This is the first critical step in helping us better understand FOXG1. As this exciting venture continues to unfold, we will be updating families with research plans and next steps. Our most sincere thanks to the FOXG1 families in helping us get to this exciting point. Let the research begin!

CONNECT WITH US ON SOCIAL MEDIA
Join our private Parent Support Group on
Facebook. There is also a group for Friends,
Family and others who wish to learn more about
FOXG1.

Be sure to 'like' the IFF Facebook page for information on FOXG1 and important news and updates from the Foundation.

We also have a private parent group on RareConnect.org for families not on social media.

Don't forget to follow us on Twitter!







International FOXG1 Foundation (IFF) is a US based 501(c)(3), parent run foundation and was created to provide family support, raise awareness of FOXG1 and to raise funds for research towards treatment and a cure for FOXG1. IFF is a stand-alone entity and in no way affiliated with any other FOXG1 groups.

For more information, please visit us at foxg1.org or contact info@foxg1.org.

## RESEARCH AND SUPPORT







Imagine IFF the seizures went away. Imagine IFF our children could say "Mom" or "Dad". Imagine IFF they could take steps by themselves. Imagine IFF they could feed themselves.

These are the dreams of the many hopeful parents of children with FOXG1. We believe that with dedicated research and funding, these dreams can be realized. This is the goal of the International FOXG1 Foundation.

Science is moving in the right direction and we are confident that dedicated research and funding can provide effective treatments for people living with FOXG1.



FOXG1 is a severe neurodevelopmental condition characterized by seizures, small head size, inability to control body movements, and lack of speech. The majority of our children cannot walk or talk. They cannot feed themselves and they struggle to communicate their most basic needs.

The mission of the International FOXG1 Foundation is to provide hope and support to individuals with FOXG1 and their families via any means possible; to facilitate discussion and fund research within the medical community, and to bring awareness and education to the public. Our goal is to fund research and provide support to FOXG1 families.

IFF has diagnoses throughout the world as well as regional representation. Please contact info@foxg1.org for more information.



## SYMPTOMS OF FOXG1\*

- Microcephaly (small head measurement)
- Partial or complete agnesis of the corpus callosum
- Reduced folds and grooves on the surface of the brain
- Smaller than usual amount of brain tissue known as white matter
- Low muscle tone
- Small hands and feet
- Seizures
- Strabismus
- Teeth-grinding
- Sleep disturbances
- Reflux
- Constipation
- Temperature regulation issues
- Flushing and/or low tolerance of heat
- · Increased susceptibility to illness
- Higher-than-average pain tolerance
- · Spontaneous laughter and/or crying
- Non-ambulatory or delayed gross and fine motor skills
- Absence of or limited speech and language skills
- Feeding problems
- Limited purposeful use of hands
- Repetitive behaviors (hand-washing, handwringing, clasping hands)
- Irritability and excessive crying
- Poor eye contact
- Regression (very rare)
- Love of water and music

\*Not all individuals present with all symptoms.