



INTERNATIONAL
FOXP1
FOUNDATION™

We are all pioneers in the field of FOXP1 genetic research

A database with particular information on individual's abilities, milestones, behaviours, and health will enable the Foundation to generate more interest from clinicians, researchers and drug developers to research, test and develop a FOXP1 natural history study, therapies or drugs. The Foundation has partnered with RareX to build the protected data base. It is now up to each of us to enroll and update the data.

How to Participate

1. Enroll
2. Complete the surveys
3. Upload the genetic report

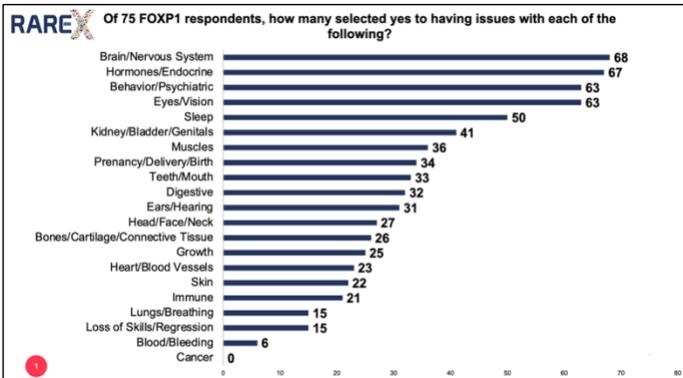


Natural History Study

The means to gather information of how FOXP1 affects a person over a lifetime. This collected data is especially valuable and can lead to new understandings, breakthroughs and treatments of our Foxes.

FOXP1 Data

A preview of the data collected as of May 2023 is available on the foxp1.org site



RAREX Issues reported by 59 FOXP1 respondents in Brain and Nervous System Survey

| Issue Reported | Percentage reporting | Number reporting | Ages at diagnosis | Ages symptoms first appeared |
|-------------------------|----------------------|------------------|---------------------------------|---------------------------------|
| Cognitive impairment | 81% | 48 | Range of: 0-3 months- 33 years | Range of: 0-3 months- 5 years |
| Coordination | 78% | 46 | Range of: 4-7 months- 33 years | Range of: 0-3 months- 5 years |
| Hypotonia | 51% | 30 | Range of: 0-3 months- 33 years | Range of: 0-3 months- 32 years |
| Hypertonia | 34% | 20 | Range of: 0-3 months- 33 years | Range of: 0-3 months- 6 years |
| Memory impairment | 29% | 17 | Range of: 2-33 years | Range of: 8-11 months- 12 years |
| Abnormal EEG | 15% | 9 | Range of: 0-3 months- 28 years | Range of: 0-3 months- 28 years |
| Headaches and Migraines | 14% | 8 | Range of: 2-24 years | Range of: 2-17 years |
| Seizures | 14% | 8 | Range of: 8-11 months- 28 years | Range of: 8-11 months- 28 years |
| Unusual movements | 10% | 6 | Range of: 4-7 months- 17 years | Range of: 4-7 months- 24 years |
| Cerebral Palsy | 7% | 4 | Range of: 8-11 months- 33 years | Range of: 0-3 months- 27 years |

RAREX Issues reported by 61 FOXP1 respondents in Behavior and Psychiatric Survey

| Issue Reported | Percentage reporting | Number reporting | Ages at diagnosis | Ages symptoms first appeared |
|-------------------------------------|----------------------|------------------|---------------------------------|---------------------------------|
| Short attention span | 77% | 47 | Range of: 4-7 months- 26 years | Range of: 0-3 months- 10 years |
| Impulsivity | 71% | 44 | Range of: 0-3 months- 21 years | Range of: 0-3 months- 10 years |
| Hyperactivity | 59% | 36 | Range of: 0-3 months- 27 years | Range of: 0-3 months- 9 years |
| ASD | 57% | 35 | Range of: 1-33 years | Range of: 0-3 months- 8 years |
| Difficulty making friends | 55% | 34 | Range of: 1-21 years | Range of: 1-14 years |
| Unusual Eye Gaze | 54% | 33 | Range of: 0-3 months- 33 years | Range of: 0-3 months- 10 years |
| Temper Tantrums | 54% | 33 | Range of: 0-3 months- 33 years | Range of: 0-3 months- 9 years |
| Repetitive Stereotypic Behavior | 52% | 32 | Range of: 8-11 months- 33 years | Range of: 4-7 months- 4 years |
| Difficulty with nonverbal behaviors | 46% | 28 | Range of: 4-7 months- 33 years | Range of: 0-3 months- 6 years |
| Mood problems | 44% | 27 | Range of: 0-3 months- 14 years | Range of: 0-3 months- 11 years |
| Aggressive/Violent Behavior | 43% | 26 | Range of: 2-14 years | Range of: 1-11 years |
| Anxiety | 43% | 26 | Range of: 2-21 years | Range of: 4-7 months- 17 years |
| OCD | 33% | 20 | Range of: 2-27 years | Range of: 1-13 years |
| Self injurious behavior | 30% | 28 | Range of: 8-11 months- 24 years | Range of: 8-11 months- 24 years |
| Depression | 13% | 8 | Range of: 10-14 years | Range of: 7-12 years |
| Bipolar Disorder | 6% | 4 | 7 years old | Range of: 0-3 months- 14 years |

RAREX Issues reported by 56 FOXP1 respondents in Eyes and Vision Survey

| Issue Reported | Percentage reporting | Number reporting | Ages at diagnosis | Ages symptoms first appeared |
|--------------------|----------------------|------------------|---------------------------------|--------------------------------|
| Eye movement issue | 64% | 36 | Range of: 0-3 months- 32 years | Range of: 0-3 months- 32 years |
| Farsightedness | 45% | 25 | Range of: 4-7 months- 14 years | Range of: 0-3 months- 12 years |
| Nearsightedness | 27% | 15 | Range of: 4-7 months- 26 years | Range of: 4-7 months- 26 years |
| Visual impairment | 21% | 12 | Range of: 0-3 months- 4 years | Range of: 0-3 months- 4 years |
| Major vision issue | 18% | 10 | Range of: 0-3 months- 26 years | Range of: 0-3 months- 19 years |
| Ptosis | 16% | 9 | Range of: 0-3 months- 14 years | Range of: 0-3 months- 4 years |
| Optic Nerve Issue | 9% | 5 | Range of: 8-11 months- 14 years | Range of: 0-3 months- 12 years |
| Retina Issues | 4% | 2 | Range of: 19- 26 years | Range of: 19- 26 years |

RAREX Issues reported by 68 FOXP1 respondents in Heart and Blood Vessels Survey

| Issue Reported | Percentage reporting | Number reporting | Ages at diagnosis | Ages symptoms first appeared |
|------------------|----------------------|------------------|----------------------------------|----------------------------------|
| Heart defect | 15% | 10 | Range of: Before Birth- 14 years | Range of: Before Birth- 14 years |
| Abnormal EKG | 5% | 4 | Range of: 8-11 months- 7 years | Range of: 0-3 months- 2 years |
| Arrhythmia | 4% | 3 | Range of: 8-11 months- 7 years | Range of: 0-3 months- 2 years |
| Aneurysm | 4% | 3 | Range of: 0-3 months- 30 years | Range of: 0-3 months- 27 years |
| Cardiomyopathy | 3% | 2 | 8-11 months | 8-11 months |
| High cholesterol | 3% | 2 | Range of: 3 years- 16 years | Range of: 3 years- 16 years |
| Hyperlipidemia | 1% | 1 | 3 years | 3 years |

RAREX Issues reported by 72 FOXP1 respondents in Immune System Survey

| Issue Reported | Percentage reporting | Number reporting | Ages at diagnosis | Ages symptoms first appeared |
|--------------------------------|----------------------|------------------|--------------------------------|--------------------------------|
| Recurrent Infections | 17% | 12 | Range of: 4-7 months- 23 years | Range of: 0-3 months- 23 years |
| Abnormal Inflammatory Response | 7% | 5 | Range of: 0-3 months- 21 years | Range of: 0-3 months- 21 years |
| Immunodeficiency | 6% | 4 | 19 years | Range of: 1-19 years |
| Autoimmune Disorder | 3% | 2 | Range of: 4-29 years | Range of: 4-28 years |