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Early Phenotype Survey

What is the Early Phenotype Survey?

Little is known about the early psychosocial and family development of young children with neurodevelopmental disorders. Our goal is to partner with families affected by these conditions to better understand children's individualized strengths and needs.

What will participation involve?

Participation involves three activities:

(1) Online parent surveys every 6-12 months
(2) Annual or biannual phone surveys
(3) Submitting documentation of genetic diagnosis (required) and optional school and medical records

How will this project help families?

Although this project will not directly benefit participants, we hope our data will impact children with genetic syndromes by improving our understanding of early phenotypes and treatment needs. Families will receive a small gift card after each assessment for their time.

Who can participate?

We are recruiting families with children under **ages 3 years and younger** who have been medically diagnosed with :

Angelman syndrome
Fragile X syndrome
Prader Willi syndrome
Williams syndrome

How can I learn more?

Please contact Dr. Bridgette Tonnsen and her research team for more information:
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