Social and emotional characteristics of girls and young women with DDX3X-associated intellectual disability: a descriptive and comparative study.

Ng-Cordell, E., Kolesnik-Taylor, A., O'Brien, S., Astle, D., Scerif, G., & Baker, K. (2023). Journal of Autism and Developmental Disorders, 53, 3208-3219.

What did we do?

- DDX3X variants are a relatively common genetic cause of neurodevelopmental difficulties in girls and young women.
- We wanted to understand more about social and emotional difficulties in young people with DDX3X variants, because these are areas of concern highlighted to us by parents.
- To address this, we carried out a questionnaire-based study of girls and young women with DDX3X variants, compared to young people with other genetic conditions.

What did we find?

- Autism characteristics are common in young people with DDX3X variants. However, these characteristics were not more common than in young people with other genetic conditions associated with neurodevelopmental difficulties.
- Anxiety-related behaviours were more common in girls and women with DDX3X variants, e.g., shyness and social withdrawal, worries about routine, and unusual fears of sounds or objects.
- Some young people with DDX3X variants also display self-injury behaviours, such as head banging and self-hitting/biting.

How can this research help?

- We encourage families to discuss their child’s social and emotional wellbeing with health and education professionals – they may have some useful strategies to help, once an individual’s needs are recognised.

What is next?

- We are now carrying out further research focusing on anxiety, to understand how emotional difficulties relate to other aspects of development, such as self-regulation abilities, sensory processing differences, and communication skills.
- We hope to understand the different pathways which link genetic conditions, brain development and aspects of emotional wellbeing, so that support can be better targeted and more effective in the future.

Resources

- You can read the full paper [here](#).
- DDX3X-specific resources:
  - [DDX3X syndrome disorder guide](#)
  - [DDX3X Support UK](#)
  - [DDX3X Foundation](#)
- Social and emotional wellbeing resources:
  - [Mental health guide](#)
  - [Anxiety guide](#)
  - [Self-injurious behaviour guide](#)