3q29 Deletion Syndrome
Family Web-Meeting Series

This series is sponsored by:
The Emory 3q29 Project
Department of Human Genetics,
Emory University

It is funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award (EAIN #00097).
Housekeeping

• Be sure to mute your microphone when not speaking to minimize background noise.

• We will watch the chat throughout the meeting. Use the chat to:
  • post comments or questions
  • private message questions for us to raise during the session

• Clinicians or healthcare workers attending who are not not registered in the 3q29 Registry:
  • Please private message me with your name and email to include you on future communications.

• Tell us what you think. Following the session you may receive a 3-question (2 minute) survey via email for feedback on this session.
Web-Meeting Permission Form*
  *emailed with meeting link

• We are interested in the topics, issues, and research priorities that are important to you.

• This meeting will be recorded. We will also make notes about important ideas and issues that come up that could be addressed in research.

• If slides, recordings, or content from this session are made available, they will not include images, voices, or names that could allow identification of individual participants.

• You may choose to turn off audio and video feeds or leave the meeting at anytime without penalty.

Timestamp in audio file:
  00:00:09
A quick poll ...

... help us know who is here.
**3q29 Web Meeting Series 2020-2021**

Unless otherwise noted, all meetings are planned for 12-1:30 pm Eastern Time. Additional session description and speaker bios will be available on the website: https://genome.emory.edu/3q29/for-families/3q29-families-meeting/

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3q29 Deletion Syndrome

Anxiety, ADHD, and Other Neuropsychiatric Symptoms

February 2, 2021
Dr. Lindsey Burrell
Dr. Joseph Cubells
Dr. Elaine Walker
3q29 Deletion: Feeding behaviors and GI symptoms

- Any GI symptom, 81%
- Failure to thrive in infancy, 9%
- Feeding problems beyond infancy, 16%
- Constipation, 41%
- Failure to thrive beyond infancy, 41%
- Reflux, 50%
- Feeding problems in infancy, 59%

60% require a feeding tube
At least 1 anxiety disorder, 40%
18% have more than 1 anxiety disorder
(7% for individuals ages 3-17 years in general population)

Social Anxiety Disorder: 6%
Separation Anxiety: 12.5%
Specific Phobia: 19%
Generalized Anxiety Disorder: 22%

We do not see an increase in depression.
In 3q29 deletion syndrome, anxiety seems to be uncoupled from depression.
3q29 Deletion: ADHD

ADHD in 3q29 Deletion: 63%
ADHD in general population: 9%
ADHD inattentive type: 31%
ADHD combined type: 25%
ADHD hyperactive/impulsive: 3%
3q29 Deletion: Enuresis

Average age at toilet training: 4 years
Range: 2 years to “not yet"

Enuresis: a repeated inability to control urination.

22% of individuals with 3q29 deletion qualify for a diagnosis of enuresis, aged 6 – 17 years.
Questions Raised At Prior Meetings

• How does anxiety typically present in 3q29 deletion?

• What are some of the biological contributors to anxiety?

• What are the psychological effects of anxiety and mood disorders? How do these conditions play out over the lifetime?

• What treatments and medications are best for addressing anxiety?

• Are there interventions/treatments for improving GI and feeding-related issues?

• How can we communicate effectively with providers regarding the seriousness of the challenges our child faces?