

# 3q29 Deletion Syndrome Family Web-Meeting Series

It was 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 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/>

Date	Topic	Presenters
Th, 10/29/2020	Overview of 3q29 Deletion	Dr. Jennifer Mulle
Th, 12/3/2020	How your health needs are addressed in research	Dr. Sharron Close
W, 1/13/2021	Cognitive Profile & Social Disability	Drs. Celine Saulnier, Cheryl Klaiman, & Stormi White
<b>Tu, 2/2/2021</b>	<b>Anxiety, ADHD, and other neuropsychiatric symptoms</b>	<b>Drs. Lindsey Burrell, Elaine Walker, &amp; Joe Cubells</b>
M, 3/29/2021	3q29 Awareness Day Celebration	Parent Advocates
M, 5/3/2021	Mental Health & Psychosis	Drs. Elaine Walker & Joe Cubells
Th, 6/25/2021	Medical and Physical Symptoms	Drs. Rossana Sanchez & Michael Gambello
TBD-Aug 2021	Dating & Interpersonal Relationships-Parent Session	Dr. Opal Ousley
TBD-Sept 2021	Dating & Interpersonal Relationships-Young Adult Session	Dr. Amanda Palmer
F, 9/10/2021	Sharing Research Findings: How to spread the word	Drs. Jennifer Mulle & Melissa Murphy
TBD-Oct 2021	3q29 Family Camp Weekend	

# 3q29 Deletion Syndrome

Anxiety, ADHD, and Other Neuropsychiatric Symptoms

February 2, 2021

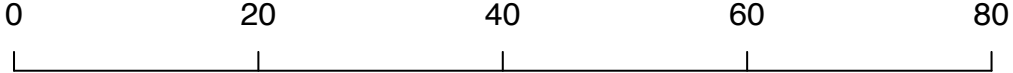
Dr. Lindsey Burrell

Dr. Joseph Cubells

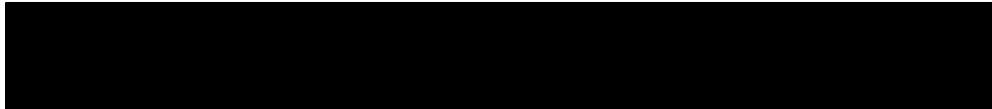
Dr. Elaine Walker



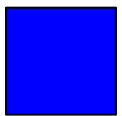
# 3q29 Deletion: Feeding behaviors and GI symptoms



Any GI symptom, 81%



Failure to thrive in infancy, 9%



Feeding problems beyond infancy, 16%



60% require a feeding tube

Constipation, 41%



Failure to thrive beyond infancy, 41%



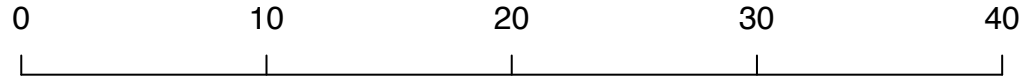
Reflux, 50%



Feeding problems in infancy, 59%



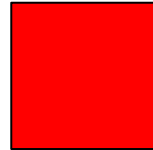
# 3q29 Deletion: Anxiety Disorders



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%



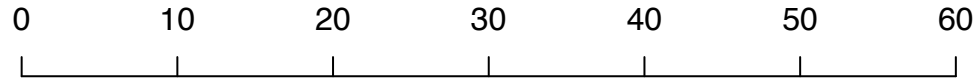
Generalized Anxiety Disorder: 22%



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.



01:07:20

# 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?