

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).



Save the date

3q29 Deletion Families Camp!



- **When:** October 1-3, 2021 (Friday afternoon – Sunday morning)
- **Where:** Camp Twin Lakes @ Camp Will-A-Way in Winder, Georgia
 - Located in Northeast Georgia about 1.25 hours from Emory University
- **What:** Outdoor explorer camp weekend for the whole family
 - Hosted by Camp Twin Lakes: <https://camptwinlakes.org/> . An organization that specializes in camping experiences for children with special needs and their families
- **Cost:** We will cover lodging and meals for the weekend. Families are responsible for travel to and from the camp.
- *Advanced registration is required. Details will be forthcoming.*

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.

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
Tu, 2/2/2021	Anxiety, ADHD, and other neuropsychiatric symptoms	Drs. Lindsey Burrell, Elaine Walker, & Joe Cubells
M, 3/29/2021	3q29 Awareness Day Celebration	Parent Advocates
M, 5/3/2021	Mental Health & Psychosis	Drs. Elaine Walker & Joe Cubells
F, 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 Planter
F, 9/10/2021	Sharing Research Findings: How to spread the word	Drs. Jennifer Mulle & Melissa Murphy
TBD-Oct 2021	3q29 Family Camp Weekend	

Contact information



Jennifer Mulle, co-PI

Department of Human Genetics

404-727-3042

jmulle@emory.edu

Melissa Murphy, co-PI

Department of Human Genetics

404-727-3446

Melissa.murphy@emory.edu