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## **Meeting Schedule**

**Meeting Date:** Tuesday, September 9, 2025

Meeting Location: <u>Virtual - Registration Link</u>

9:00 - 9:30 AM Executive Committee Meeting

Executive committee only - closed meeting

9:30 – 10:00 AM Concurrent Committee Meetings

Everyone is encouraged to participate in a committee.

Education

- Public Relations

- Professional Issues

10:00 – 11:00 AM SPARKing Better Understanding of Autism through Genomics

Wendy Chung, MD, PhD Boston Children's Hospital

11:00 – 11:30 AM General Membership Meeting

President's Report

Secretary's Report

- Treasurer's Report

Introduction of Members

Committee Reports

New Business

11:30 – 12:30 PM The All of Us Research Program: Data and Access

Dr. Tara Dutka

All of Us Research Program

12:30 – 1:00 PM BREAK

1:00 – 2:00 PM Handful of Hope: Kinsley's journey having a rare disease.

Patricia Geurds

Parent of a child with FOXG1

2:00 – 3:00 PM Co-Supervision in Genetic Counseling Training

Elizabeth Francisco, MS, CGC

LabCorp Genetics

3:00 PM Adjournment

<sup>\*\*</sup> For more information about the educational presentations, please refer to the following pages. \*\*



# **Summary of Educational Presentations**

## **SPARKing Better Understanding of Autism through Genomics**

Speaker: Wendy Chung, MD, PhD

10:00 – 11:00 AM (60 minutes, 1 contact hour)

## Objectives:

1. Identify how to order and interpret genetic/genomic test results for autism.

2. Interpret the family history of neurobehavioral conditions (excluding autism) to explain its relevance to the genetic contributions to autism.

Summary: We will review the genomic architecture of autism and how that differs with other co-occuring diagnoses such as intellectual disabilities. We will review the sex bias in autism with a 4:1 male:female prevalence. We will also review the spectrum of neurobehavioral diagnoses associated with inherited rare variants and autism.

## The All of Us Research Program: Data and Access

Speaker: Tara Dutka, PhD

11:30 AM – 12:30 PM (60 minutes, 1 contact hour)

#### Objectives:

- 1. Identify the genomic data available through the All of Us Research Program.
- 2. Demonstrate how to access the data through the Research Workbench

Summary: This presentation will describe the All of Us Research Program and the data it has made available. There will be a particular emphasis on genomic data availability. The presentation will also describe how to access the data and/or participate in the program.

## Handful of Hope: Kinsley's journey having a rare disease.

Speaker: Patricia Geurds

1:00 – 2:00 PM (60 minutes, 1 contact hour)

#### Objectives:

- 1. Describe the lived experience of individuals with rare diseases by highlighting the challenges and triumphs, using my daughter's journey as a case example.
- 2. Explain the impact of healthcare professionals' roles beyond diagnosis, focusing on how their interactions with patients and families during testing, research, and discovery can provide support, education, and emotional comfort.

Summary: This presentation will provide a "bird's eye view" one that most never see; into our family's world, both day-to-day and through the years. My unique perspective on loving rare and how I feel about her diagnostic journey may surprise people, but that is why Kinsley's story is essential - filled with gratitude to all those who have worked to help Kinsley, some funny stories, and heartfelt ones as well. I hope everyone will walk away with a bit of inspiration!



## **Co-Supervision in Genetic Counseling Training**

Speaker: Elizabeth Francisco, MS, CGC 2:00 – 3:00 PM (60 minutes, 1 contact hour)

### Objectives:

- 1. Identify the benefits and limitations of co-supervision for supervisors
- 2. Recognize strategies to optimize co-supervision rotations for students

Summary: We will review the experiences of students and supervisors with co-supervision rotations. In examining these experiences, we will discuss benefits and limitations to both supervisors and students. Using this information, we will evaluate ways to optimize these types of rotations for student benefit.