HGANJ
Human Genetics Association of New Jersey

Meeting Schedule

Meeting Date: Tuesday, September 8, 2026

Meeting Location: Virtual - Registration Link

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. 1. Education 2. Public Relations 3. Professional Issues
10:00 – 11:00 AM	**Bridging Community and Industry: The Role of Advocacy Organizations and Patient Advocacy GCs in Rare Disease Drug Development** Niki Armstrong, MS, CGC *Foundation for Angelman Syndrome Therapeutics*
11:00 – 11:15 AM	**Ambry Genetics: Promoting Equity in Genomic Medicine** Heather Rocha, MS, CGC
11:15 – 11:45 AM	**General Membership Meeting**
11:45 AM – 12:15 PM	BREAK
12:15 – 1:15 PM	**Hospital-wide implementation of rapid genome sequencing** Tara Wenger, MD, PhD *Children's Hospital of Philadelphia*
1:15 – 2:15 PM	**Overview of BRIDGES-NBS Study, the role of newborn screening programs, and APHL** Guisou Zarbalian, MS, MPH *Association of Public Health Laboratories*
2:15 – 2:30 PM	BREAK
2:30 – 3:30 PM	**Technology and Supervision: Navigating AI, Telehealth, and Equity in Student Rotations Training** *Elizabeth Francisco, MS, CGC* *LabCorp*
3:30 PM	**Adjournment**

*** For more information about the educational presentations, please refer to the following pages. ***

This event has been submitted to the National Society of Genetic Counselors (NSGC) for approval of 0.40 Category 1 CEUs. The American Board of Genetic Counseling (ABGC) accepts CEUs approved by NSGC for purposes of recertification. Approval for the requested CEUs and Contact Hours is currently pending.

Summary of Educational Presentations

Bridging Community and Industry: The Role of Advocacy Organizations and Patient Advocacy GCs in Rare Disease Drug Development
Speaker: Niki Armstrong, MS, CGC
10:00 – 11:00 AM (60 minutes, 1 contact hour)

Objectives:
1. Describe the role of patient advocacy organizations in rare disease therapeutic development
2. Explain how genetic counselors in patient advocacy organizations support patient education and drug development throughout the therapeutic development process.

Summary: Patient advocacy organizations (PAOs) play a critical role in rare disease therapeutic development, from educating communities, identifying unmet needs, and supporting trial readiness to funding early-stage research and facilitating communication between the stakeholders. Genetic counselors embedded in advocacy can help families understand clinical trials and the drug development process, navigate genetically-based inclusion criteria, and consider the benefits and limitations of trial participation, while also supporting ethical engagement with industry. This session will highlight how PAO and patient advocacy GCs contribute to patient-centered development of rare disease therapeutics and strengthen the bridge between the patient community and translational research.

Hospital-wide implementation of rapid genome sequencing
Speaker: Tara Wenger, MD, PhD
12:15 – 1:15 PM (60 minutes, 1 contact hour)

Objectives:
1. Define exclusion-based rapid genome sequencing
2. Describe relative impact of genome sequencing on critically ill vs. non-critically ill hospitalized children
3. Identify two ways that early genetic diagnosis can impact care for hospitalized children

Summary: Rapid genome sequencing has become increasingly common in intensive care settings, particularly with infants under a year of age. This presentation will describe the impact of transition to hospital-wide rapid genome sequencing as a first-line test at Seattle Children's Hospital. Following the transition to first-tier sequencing, there was an increase in the number of diagnoses made as well as earlier, precise genetic diagnosis, allowing earlier initiation of targeted therapies.

Overview of BRIDGES-NBS Study, the role of newborn screening programs, and APHL
Speaker: Guisou Zarbalian, MS, MPH
1:15 – 2:15 PM (60 minutes, 1 contact hour)

Objectives:
1. Identify the seven pilot NBS programs selected for this study
2. Explain the role and involvement of NBS programs in the BRIDGES-NBS study

This event has been submitted to the National Society of Genetic Counselors (NSGC) for approval of 0.40 Category 1 CEUs. The American Board of Genetic Counseling (ABGC) accepts CEUs approved by NSGC for purposes of recertification. Approval for the requested CEUs and Contact Hours is currently pending.

Summary: This session will provide an overview of the BRIDGES-NBS study, including its primary goal, how newborn screening (NBS) programs are involved, and how “feasibility” is being defined for this study. An overview of the newborn screening system and process will be provided as well as background on NBS program operations. The presentation will also cover the Association of Public Health Laboratories’ (APHL’s) role both in supporting NBS programs generally and in the BRIDGES-NBS study.

Technology and Supervision: Navigating AI, Telehealth, and Equity in Student Rotations Training
Speaker: Elizabeth Francisco, MS, CGC
2:30 – 3:30 PM (60 minutes, 1 contact hour)

Objectives:

1. Identify the risks of AI in regard to stereotyping, data privacy, and patient information with AI
2. Discuss the concept of "deskilling" in the world of AI learning.
3. Review the benefits and challenges of telehealth rotations (accessibility, flexibility, convenience)
4. Evaluate methods used by current supervisors to promote inclusivity with technology

Summary: This presentation will focus on the new world of supervision in an evolving technology landscape. We will walk through the newest major development in the technical world, A.I., how that impacts student learning, and what safeguards should be considered. We will also look at access and inclusion in student rotations and how technology has impacted students with varying needs.