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## Meeting Schedule

**Meeting Date:** Tuesday, September 10, 2024  
**Meeting Location:** Virtual Meeting sponsored by Kean University  
[Registration Link](#)

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- 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
- 10:15 – 11:15 AM **Genetic Detective Work: Investigating Gene-Disease Characterization and Variant Interpretation**  
Catherine Mayo, MS, CGC and Margo Gallegos, MS, CGC  
*Ambry Genetics*
- 11:30 AM – 12:00 PM **General Membership Meeting**  
- President's Report  
- Secretary's Report  
- Treasurer's Report  
- Introduction of Members  
- Committee Reports  
- New Business
- 12:00 – 12:30 PM **Break**
- 12:30 – 2:00 PM **Advances and Curative Options for Sickle Cell and Thalassemia with Patient Story**  
Alexis Thompson, MD, MPH  
*Children's Hospital of Philadelphia*
- 2:15 – 3:15 PM **Bench to Bedside Development of the First FDA Approved Gene Therapy for Epidermolysis Bullosa**  
M. Peter Marinkovich, MD  
*Stanford University School of Medicine*
- 3:30 – 5:00 PM **Incorporating a Restorative Justice Framework Within Genetic Counseling Clinical Supervision**  
Joselyn Diaz, MS, CGC and Cecily Wang, MS  
*MGH Institute of Health Professions*
- 5:00 PM **Adjournment**

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



## Summary of Educational Presentations

### **Genetic Detective Work: Investigating Gene-Disease Characterization and Variant Interpretation**

*Speakers: Catherine Mayo, MS, CGC and Margo Gallegos, MS, CGC*

10:15am – 11:15am (60 minutes, 1 contact hour)

**Objectives:**

1. Explain the impact of gene-disease characterization on understanding the causes of genetic disorders.
2. Describe the challenges involved in interpreting genetic variants and their effect on disease development.

**Summary:**

The objectives aim to educate the audience about the concept and importance of gene disease association on genetic testing and empower audience members to apply these skills and be more critical genetic testing consumers.

### **Advances and Curative Options for Sickle Cell and Thalassemia with a Patient Story**

*Speakers: Alexis Thompson, MD, MPH, and a Patient*

12:30pm – 2:00pm (90 minutes, 1.5 contact hours)

**Objectives:**

1. Describe new disease modifying therapies for sickle cell and thalassemia.
2. Provide updates on curative options for sickle cell and thalassemia focused on gene therapy.

**Summary:**

Hemoglobinopathies such as sickle cell disease and thalassemia are among the most common inherited blood disorders. Advances in care are improving outcomes and recent results of gene therapy trials have open the door for potential new curative approaches. This presentation will provide updates on disease modifying therapies and gene therapies for these conditions.

### **Bench to Bedside Development of the First FDA Approved Gene Therapy for Epidermolysis Bullosa**

*Speaker: M. Peter Marinkovich, MD*

2:15pm – 3:15pm (60 minutes, 1 contact hour)

**Objectives:**

1. Examine the therapeutic landscape available for dystrophic epidermolysis bullosa.
2. Summarize the different forms of gene therapy, ex vivo versus in vivo.

**Summary:**

Dystrophic epidermolysis bullosa, clinical and molecular features, will be described. Several different forms of gene therapy will be presented. Bench to bedside development of beremagene gepervavec will be presented as the first FDA approved therapy for dystrophic epidermolysis bullosa.

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CHRISTINA BOTTI, MS, CGC, **PRESIDENT**  
KRISTEN ONDY, MS, CGC, **PRESIDENT-ELECT**  
SARAH NASHED, MS, CGC, **TREASURER**  
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FRANCESCA SPINOSI, MS, CGC, **MEMBER-AT-LARGE**

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## **Incorporating a Restorative Justice Framework Within Genetic Counseling Clinical Supervision**

*Speakers: Joselyn Diaz, MS, CGC and Cecily Wang, MS*

3:30pm – 5:00pm (90 minutes, 1.5 contact hours)

### Objectives:

1. Describe the principles of restorative justice and how it challenges supervisor-supervisee power dynamics.
2. Apply a restorative justice framework to case scenarios to interrupt and address microaggressions in clinical supervision.

### Summary:

The purpose of this presentation is to review power dynamics within genetic counseling supervision and how microaggressions can harm the student-supervisor relationship. We will introduce the framework of restorative justice as a way to address, repair and foster relationships within the genetic counseling supervision setting.

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*All talks/modules above are presented via PowerPoint presentations and sound. The presenters have visual aids and key points listed on their PowerPoint presentations.*