



NERGG 42nd Annual Educational Conference 2019

December 5–6, 2019

Sheraton Portsmouth Harborside Hotel, Portsmouth, New Hampshire

FINAL AGENDA

Day One: December 5, 2019

9:00 Registration and Coffee

Lobby

Sponsored by Invitae

9:50 Welcome

Ballroom

– Ms. Mary-Frances Garber, MS, CGC President, NERGG

10:00 Angelman Syndrome: Phenotypic Spectrum & Management Ballroom

- Dr. Wen-Hann Tan, Boston Children's Hospital, Genetics & Genomics Div.
- Dr. Noelle Germain, Stem Cell Core, UCONN Health
- Mr. Tim Bousum, VP, Angelman Syndrome Foundation

11:00 Genetic Test Utilization and Management

Ballroom

– Mr. Andrew McCarty, Lab Genetics Counselor, Perkin Elmer Genomics

12:00 Lunch

Lobby

Visit with Exhibitors

Langdon

Day One: December 5, 2019

1:00 Finding Hope in Uncertainty

Ballroom

Panel co-sponsored by NERGG and NERGN

- Dr. Susan Zimmerman, ABLE NH
- Ms. Tara Townsend-Hayes, Rhode Island Parent Information Network
- Dr. Peter Antal, Co-Director, New England Regional Genetics Network
- Ms. Jennifer and Mr. Shawn Bertrand, Community Crossroads Inc.
- Ms. Chloe Bertrand, Self-Advocate

2:30 Hereditary Transthyretin Amyloidosis: Diagnosis, Treatment, and Genetic Considerations

Ballroom

Sponsored by Akcea Therapeutics

- Dr. Sami Khella, Chief, Dept. of Neurology at Penn Presbyterian MC
- Mr. Brian Schoenfeld, MS, CGC

3:30 Beverages and Snacks

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4:00 NERGG Annual Meeting

Ballroom

All are invited

4:30 CANNEW Presentations

Ballroom

Research abstracts and case studies

6:30 Reception: Cocktails and Hors d'Oeuvres

Lobby

7:00 Dinner

Ballroom

Day Two: December 6, 2019

7:30 Breakfast and Breakfast Speaker

Lobby

Sponsored by Variantyx, Inc.

**8:00 Whole Genome Sequencing and the Laboratory
Perspective: Name that Disorder!**

Ballroom

Dr. Christine Stanley, Director, Clinical Genomics, Variantyx

**9:00 Whole Genome Sequencing and the Research Perspective:
Family Experience with Late Diagnosis and Intervention**

Ballroom

- Ms. Grace VanNoy, MS, CGC Broad Institute of Harvard and MIT*
- Ms. Melanie O’Leary, MS, LGC Broad Institute of Harvard and MIT*

10:15 Break

**10:45 A Surgeon’s Role in Communicating the Genetic Aspects
of Breast Cancer**

Ballroom

- Dr. David Coppola, Seacoast General Surgery PC*

12:00 Lunch

Lobby

Visit with Exhibitors

**1:00 Glycogen Storage Disease Type Ia: 40 Years of
Progress from Cornstarch to Gene Therapy**

Ballroom

- Dr. David Weinstein, GSD Program Director, CT Children’s Medical Ctr.*

2:15 Beverage/Snacks

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**2:30 Duchenne Muscular Dystrophy: Overview of
Care Needs for Patient and Family**

Ballroom

- Dr. Brenda Wong, Director of Interdisciplinary DMD Clinic, UMASS Memorial Medical Center*
- Ms. Jennifer McNary, DMD Advocate and Consultant*

3:30 Wrap-Up and Adjournment

Ballroom

- Mr. Sam Drazin, newly installed NERGG President*
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