



NERGG 45th Annual Educational Conference 2022

December 8–9, 2022

A virtual meeting supported by the New England Regional Genetics Network

Day One Agenda

Day One: December 8, 2022

11:45 Welcome and Housekeeping Details

- Kathleen Swenson, MPH, MS, CGC, 2022 President, NERGG
- Karen Volle, Project Manager, NERGN

12:00 Sickle Cell Disease: Overview, Treatment, and Future Directions

- Jean-Antoine Ribeil, MD, Clinical Director, Boston University Center of Excellence in Sickle Cell Disease

1:00 The Personal Genetics Education (pgEd) Project at Harvard Medical School

- Marnie Gelbart, PhD, Director of Programs, Department of Genetics
- Robin Bowman, M. Ed., Director of Education and Engagement, Department of Genetics

2:00 Break/Meet Your Partners

Greetings from our partners and exhibitors

2:30 Beyond the Pale: A Closer Look at Albinism

- Karen Bly, BS, BA, Director, National Organization for Albinism & Hypopigmentation (NOAH), Sandy Lake, PA
- Kaitlin O'Connell, MS, CGC, Ocular Genetic Counselor at Ocular Genomics Institute, Massachusetts Eye and Ear
- Lee Laughlin, M. Ed., Freelance writer, cofounder of NOAH, and a person with albinism
- Alix Laughlin, RN

3:30 Prenatal Exome Testing

Sponsored by GeneDx

- Erin Ryan, MS, CGC, Clinical Service Liaison, Genomics Specialist, Danville, PA

4:30 Break/Meet Your Partners

Greetings from our partners and exhibitors

5:00 Closing Remarks

- Kathleen Swenson, MPH, MS, CGC, 2022 President, NERGG



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Day Two Agenda

Day Two: December 9, 2022

11:45 Welcome and Housekeeping Details

- Kathleen Swenson, MPH, MS, CGC, 2022 President, NERGG
- Karen Volle, Project Manager, NERGN

12:00 CANNEW Research Updates

Prioritization of Gene-Based Therapies for Neurodevelopmental Disorders

- Maya Chopra, MBBS, FRACP, Director of Translational Genomic Medicine at the Rosamund Stone Zander Translational Neuroscience Center, Boston Children's Hospital

National Organization of Rare Disorders (NORD) Rare Disease Centers of Excellence: Boston Children's Genetics and Genomics

- Olaf Bodamer, MD, PhD, Associate Chief of Genetics & Genomics, Boston Children's Hospital

1:00 The Genetics of Spina Bifida

- Richard Finnell, PhD, Director, Finnell Birth Defects Lab, Baylor College of Medicine, Houston, TX
- M. Elizabeth Ross, MD, PhD, Director, Center for Neurogenetics, Weill Cornell Medical College, NYC
- Jean Bertschman, BA, Director, Spina Bifida Association of Greater New England, Milford, MA
- Judy Thibadeau, RN, MN, Director of Research and Services, Spina Bifida Association, Arlington, VA
- Nicholas and Julia Bellerose, Family Speakers

2:15 Break/Meet Your Partners

Greetings from our partners and exhibitors

2:45 The Genetics of Autism

- Naomi Meeks, MD, Clinical Director, Children's Hospital Colorado Precision Diagnostics Laboratory, Aurora, CO
- Ryan Doan, PhD, Clinical Molecular Geneticist, Division of Genetics and Genomics, Boston Children's Hospital
- Brenda Dater, MPH, MSW, Executive Director, Asperger/Autism Network (AANE), Watertown, MA
- Paul Micalcuff, BE, BTech, Founder and Director of Autism from the Inside, Melbourne, Australia

4:00 Break/Meet Your Partners

Greetings from our partners and exhibitors

4:30 Closing Statements and Evaluations

- Tara Hayes, BS, CCHW, 2023 NERGG President