New England Regional Genetics Group

Genetic Counseling: Moving into the Future

May 4, 2018 at the
Doubletree Boston North Shore
50 Ferncroft Road, Danvers, MA 01923

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Agenda

7:00 Registration and Continental Breakfast
7:50 Welcome remarks from Lisa Brailey, MD, President of NERGG
8:00 Marina DiStefano, PhD, "Interpretation of Sequence Variant Pathogenicity"
9:00 Deborah Rivlin, "Overview of The Children’s Room: Caring Support for Grieving Children, Teens and Families Programs and Services"
10:00 Break
10:15 Allison Cirino, CGC, "Keeping Pace with Cardiovascular Genetics: Updates on the Genetics of Inherited Heart Disease"
11:15 Kate Reed, MPH, ScM, CGC, "Education in a Next-Gen World: Approaches for Training our Colleagues"
12:15 Lunch
1:00 Kimberly LeBlanc, CGC, Emily Glanton, CGC, & Lauren Briere, CGC, Undiagnosed Diseases Network, "The Multidisciplinary Clinical and Research Evaluation of Patients with Rare and Undiagnosed Conditions"
2:00 Sally Rosengren, MD, "Would You Miss Mucopolysaccharidosis (MPS)?"
3:00 Break
3:15 Julie McKinney, "Only 10 in the World? A Family's Journey with a Rare Genetic Disorder, and Some Unique New Resources to Help Other Families Find Support"
4:15 Sue Findlay, "n of One"
5:15 Networking Reception
6:00 Adjourn
Speakers

Marina DiStefano, PhD, received her Ph.D. in molecular medicine from UMass Medical School in Worcester. She is currently a Clinical Molecular Genetics Fellow in the Harvard Genetics Training Program. She is based at the Laboratory for Molecular Medicine and is also a part-time postdoctoral research fellow for the Clinical Genome Resource (ClinGen) with a focus on gene curation and specifying the ACMG guidelines for interpreting variants in genes associated with genetic hearing loss.

Deborah Rivlin has been the Director of Education and Training at The Children’s Room for the past 10 years. Previously, she was the Director of THE CIRCLE at Boston Medical Center’s Good Grief Program. She received her Masters in Applied Human Development and Guidance from Columbia University.

Allison Cirino, MS, CGC received her BS in Biology with a minor in Psychology from James Madison University in Harrisonburg, Virginia. She received an MS in Genetic Counseling from the Graduate Program in Genetic Counseling at Northwestern University. Since 2004, Allison has been a genetic counselor in the Brigham and Women’s Hospital Cardiovascular Genetics Center where she is involved in both patient care and ongoing clinical research activities in inherited heart disease. She is currently the co-chair of the National Society of Genetic Counselors Cardiovascular SIG as well as a member of the ClinGen Inherited Cardiomyopathy Expert Panel. She also serves as the NSGC Liaison to the American Heart Association Genomics and Precision Medicine Council.

Kate Reed, CGC is the director of the Clinical and Continuing Education Program at The Jackson Laboratory (JAX) and a board certified genetic counselor. She has over ten years of experience in clinical genetics, healthcare provider education, and program development. At JAX, she directs the clinical education effort, which focuses on developing and implementing education to facilitate the integration of genetics and genomics into clinical practice. The programs are developed in collaboration with a variety of healthcare providers and cover topics most pertinent to the intended audience, including genetic risk assessment, precision medicine, and somatic testing for cancer. Prior to joining JAX in 2013, Kate worked at the National Coalition for Health Professional Education in Genetics (NCHPEG), a non-profit focused on increasing integration of genetics into clinical practice through education. Kate also has practiced as a clinical genetic counselor in a variety of pediatric and adult settings.

Kimberly LeBlanc, MS, CGC, is a genetic counselor and the Associate Director of Research Operations at the Undiagnosed Diseases Network (UDN) Coordinating Center in the Department of Biomedical Informatics at Harvard Medical School. The UDN Coordinating Center oversees the activities of the UDN, a network of seven clinical sites and research cores that evaluate patients with difficult-to-diagnose conditions. As part of the UDN Coordinating Center, Kimberly supervises the direct interactions with participants, including helping participants navigate the UDN application, evaluation, sequencing, and research process. Kimberly also works with investigators from the sites and cores to develop network-wide clinical and participant engagement protocols. Kimberly received her master’s degree in Human Genetics and Genetic Counseling from the Stanford University School of Medicine.

Emily Glanton, MS, CGC is a board-certified genetic counselor and project manager for the Undiagnosed Diseases Network (UDN) Coordinating Center in the Department of Biomedical Informatics at Harvard Medical School. The UDN Coordinating Center oversees the activities of the UDN, a network of seven clinical sites and research cores that evaluate patients with difficult-to-diagnose conditions. As part of the UDN Coordinating Center, Emily leads participant research engagement initiatives and manages network-wide operations. Emily is fluent in Spanish and received her bachelor’s in Spanish from UCLA. Emily received her master’s in genetic counseling from the Boston University School of Medicine.

Lauren Briere, MS, CGC is the genetic counselor and clinical coordinator for the Harvard Clinical Site of the Undiagnosed Diseases Network (UDN) at Massachusetts General Hospital (MGH). Lauren’s responsibilities include reviewing applications, collecting and reviewing past medical records and family history, consenting study participants, coordinating clinical and research evaluations through the UDN, and genetic counseling. Lauren received her master’s degree in genetic counseling from the University of California, Irvine in 2006 and is a board-certified and MA-licensed genetic counselor. Prior to joining the UDN at MGH, she worked as a prenatal genetic counselor at Beth Israel Deaconess Medical Center.

Sally Rosengren, MD retired from the Division of Human Genetics at UCONN Health in 2016, after many years of providing medical care to genetic patients at UCONN and CT Children’s Medical Center. One of the areas she specialized in was the diagnosis, management, and treatment of patients with mucopolysaccharidosis (MPS). Since retirement, Dr. Rosengren has been a consultant for the pharmaceutical company BioMarin, developing and delivering educational programming on MPS conditions. When she is not consulting, lecturing or teaching, she is an avid beekeeper.

Julie McKinney is a health literacy specialist with a focus on resources for professionals and communities, plain language materials for the public, and helping to make health information easier to understand. She has written resource guides, trained professionals, developed curricula and written material for audiences with lower literacy skills. She now works with Exceptional Lives, creating easy-to-read information to help parents of children with disabilities navigate complicated processes and get the benefits, services and support they need. As the parent of a child with a disability, she holds a deep understanding and passion for this challenge.