

# NERGG 43<sup>rd</sup> Annual Educational Conference 2020

December 3-4, 2020

A virtual meeting co-sponsored by the New England Regional Genetics Network



# **DAY ONE AGENDA**

Day One: December 3, 2020

## 1:00 Welcome and Housekeeping Details

- Sam Drazin, President, NERGG
- Cynthia Ingham, Director, NERGG
- Karen Volle, Project Coordinator, NERGN

## 1:15 Population Health

# Sponsored by Invitae

- Eden Haverfield, PhD, FACMG

## 2:15 Emerging Gene-Based Treatments for Neurological Disorders, Part 1: Ataxia Telangiectasia

Sponsored by Translational Neuroscience Center/The Yu Laboratory, Boston Children's Hospital

- Timothy Yu, MD, PhD
- Victoria Suslovitch, MS, CGC
- Ms. Jennifer Thornton, Executive Director, AT Children's Project

## **3:15** Break

# 3:30 Emerging Gene-Based Treatments for Neurological Disorders, Part 2: Epilepsy

Sponsored by Translational Neuroscience Center/The Yu Laboratory, Boston Children's Hospital

- Mustafa Sahin, MD, PhD
- Annapurna Poduri, MD, MPH

## 4:30 Meet Your Partners

Greetings from our sponsors



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# **DAY TWO AGENDA**

# Day Two: December 4, 2020

## 9:00 Prenatal Diagnosis: Bridging the Gap between the Laboratory and the Clinic

# **Sponsored by Prevention Genetics**

- Christele du Souich, MSc, CGC, CCGC
- Diane Allingham-Hawkins, PhD, FCCMG, FACMG

# 10:00 Facioscapulohumeral Dystrophy

# **Sponsored by PerkinElmer**

- Madhuri Hegde, PhD, FACMG

## 11:00 Break

# 11:15 Our Journey with Justin: Embracing Life with a Rare Disease (Hunter Syndrome)

- Steven Gentile, MBA
- Kimberly Gentile, MBA

## 12:15 Closing Statements and Evaluations

- Kunal Sanghavi, newly installed NERGG President

## 12:30 Meet Your Partners

Greetings from our sponsors

Thanks for joining us! Don't forget to fill out your evaluations and GC CEU Self Reporting forms, if applicable.



Karen Volle, Project **Coordinator, NERGN** 



Eden Haverfield, PhD, **FACMG** 





Timothy Yu, MD, PhD Victoria Suslovitch, MS, CGC



Mustafa Sahin, MD, PhD



Annapurna Poduri, MD, **MPH** 



Christele du Souich, MSc, CGC, CCGC



Diane Allingham-Hawkins, PhD, FCCMG, FACMG



Madhuri Hegde, PhD, **FACMG** 



Steven Gentile, MBA



Kimberly Gentile, MBA

## **PRESIDENT**

Samuel Drazin, Executive Director **Changing Perspectives** Bradford, VT

#### PRESIDENT ELECT

Kunal Sanghavi, MBBS, MS, LCGC Program Manager, Genetic Counseling The Jackson Laboratory for Genomic Medicine Farmington, CT

## **IMMEDIATE PAST PRESIDENT**

Mary-Frances Garber, MS, CGC Listening, Reflecting, Healing Needham, MA

#### **TREASURER**

Maria Gyure, MS, LCGC Program Director, Genetic Counseling Program Cynthia Ingham, RN, BSN University of Connecticut, Storrs, CT

## **SECRETARY**

Kimberly Zayhowski, MS, CGC Genetic Counselor University of Massachusetts Medical Center, Worcester, MA

## **EXECUTIVE DIRECTOR**

director@nergg.org Burlington, VT

### STATE REPRESENTATIVES

## CONNECTICUT

Practitioner: Lisa Louise Brailey, MD Public Health: Marie Burlette, RN, BSN, MPH

Consumer: Peggy Sweeney

#### MAINE

Practitioner: Tom Brewster, MD Public Health: Holly Richards, MPH Consumer: Abby Pearson, MS

## **MASSACHUSETTS**

Practitioner: David Harris, MD Practitioner (alternate): Catherine Nowak, MD Public Health: Eirini Nestoridi, MD Consumer: Sophia Zilber, MA

#### **NEW HAMPSHIRE**

Practitioner: Erica Stelmach, MS, LGC Practitioner (alternate): Lisa Demers, MS, LGC Public Health: Vacant

Consumer: Joanne Huff, RN

### **RHODE ISLAND**

Practitioner: Kerry Ahern, MS, CGC Practitioner: Jennifer Schwab, MS, CGC Public Health: Emily Eisenstein, MPH Consumer: Tara Hayes, BS, CCHW

## **VERMONT**

Practitioner: Christine Giummo, MS, CGC Public Health: Sydney Williamson-White,

BSN, RN

Consumer: Allison Wood, MS