Genetic Education Materials for School Success
New England Regional Genetics Networks (NERGN)

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NH-ME LEND

Introduction

GEMSS Project Activities

- ✓ Worked closely with the NERGN team to bring an educational perspective to the materials
- ✓ Reviewed each condition, focusing on Academic Support & Behavioral Support
- ✓ Ensured a more inclusive language was used
- ✓ Updated terms focusing on a person-centered perspective
- ✓ Removed any unnecessary redundancy
- ✓ The result is 37 simplified booklets for school teams

Background

- 1977 The New England Regional Genetics Group (NERGG) began as a "vehicle for education and collaboration".
- 1999 NERGG incorporated as a non-profit organization, as it is today.
- 2007 The New England Genetics Collaborative (NEGC) was 1 of 7 Regional Genetic Networks funded by Health Resources Services Administration (HRSA).
- 2017 NEGC was restructured as NERGN.
  - NERGN goals:
    - Supporting families and partnering with family-led organizations
    - Educating non-genetic providers about genetics to improve coordinated care
    - Connecting people, especially with genetic services
    - GEMMS – a wealth of genetic resources
- May 2024, The Regional Genetics Network system, including NERGN, will discontinue. The work to make life better for families on their genetic journey will happen but in different ways.

Acknowledgments

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Genetic Conditions within GEMSS

- 22q Deletion Velocardiofacial
- Achondroplasia
- Aicardi Syndrome
- Angelman Syndrome (AS)
- Autism Spectrum Disorder (ASD)
- Charge Syndrome
- Congenital Heart Defects
- Cornelia De Lange Syndrome (CDLS)
- Cystic Fibrosis
- Down Syndrome
- Ehlers-Danlos Syndrome (EDS)
- Fragile X
- Fetal Alcohol Spectrum Disorders (FASDS)
- Galactosemia
- Kabuki Syndrome
- Klinefelter Syndrome
- Marfan Syndrome
- MCDA
- MECP2 Duplication
- Mitochondrial Disorders
- MPS Disorders (Hurler/Hunter/ Morquio)
- Neurofibromatosis 1
- Noonan Syndrome
- Phenylketonuria (PKU)
- Prader-Willi
- Rett/Rett Variant Syndrome
- Rubinstein-Taybi Syndrome
- Russell-Silver Syndrome
- Sickle Cell Disease
- SMA, MD & other Neuromuscular Disorders
- Smith-Magennis Syndrome
- Sotos Syndrome
- Tuberous Sclerosis
- Turner Syndrome
- Urea Cycle Disorders
- VLCAD
- Williams Syndrome
- Undiagnosed Medical or Developmental Conditions

Summary

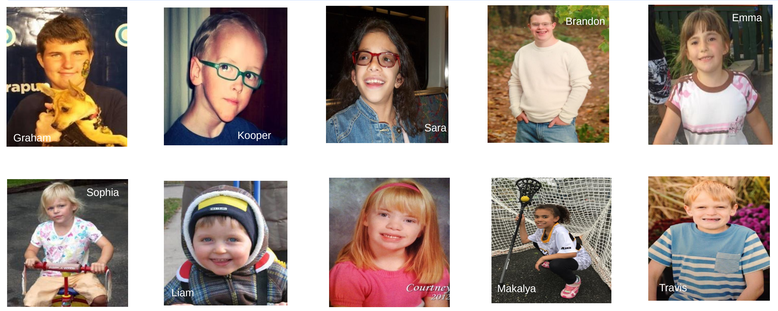
NERGN inspired many adventures, introducing me to a whole new world.

- Genetics Navigators,
- Mountain State Genetic Navigators (MSRGN)
- Newborn Screening (NBS)
- Rare Diseases and the Rare Disease Advisory Council

They were open to new ideas that I have been fortunate to learn through UNH and NH-ME LEND.

- Words matter. Avoid using stigmatizing words
- Improve the lives of children with neurodevelopmental disabilities and their families
- Promoting a positive strengths-based model

Meet a Child



nergn NEW ENGLAND REGIONAL GENETICS NETWORK

Hearing a family's story about their genetic journey, like you'll find on GEMSS, is an antidote for isolation. It builds hope, and nothing is more important. ~Karen

The world for families with rare and genetic conditions can be so hard. We hope that NERGN was able to educate providers and empower patients to make their lives a little easier." ~ Angela

Benjamin Franklin said, "Tell me and I forget. Teach me and I remember. Involve me and I learn". Because the LEND program focuses on involvement, you have learned much, Stephanie. And we have learned from YOU. ~Ed

I am so excited to hear that the National Family Voices will be the new home for GEMSS in May. I hope that families can share this tool with their child's educators to create a stronger well-informed connected team. ~Stephaine

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