

NHPCC Genetics Work Group

Charge of group:

Identify gaps in genetic services and possible resources to fill these gaps

Identify/develop educational materials for patients and providers

Identify genetic counselors who serve the HTC patients and families

Outreach to genetics counselors not at the HTCs

Increase knowledge of blood disorders among external genetic counselors

Committee co-chairs:

Michelle Alabek, MS, CGC & Danielle Deery, JD

Committee Members:

Kate Bergstrom, MS, CGC; Robina Ingram-Rich, BSN, MS, MPH; Meg Bradbury, MS, CGC; Kristin Nunez, MS, CGC; Randal Curtis, MBA; Matthew Pace, consumer; Stephanie Dansker, MA; Marianna Raia, MS, CGC; Sumeda Ghate, MS, CGC; Elizabeth Varga, MS, CGC; Meadow Heiman, MS, CGC

NHPCC representative:

Ann Forsberg, MPH



Current Projects

- Characterize genetic services provided to patients with bleeding disorders across the nation through an e-survey distributed through the American Board of Genetic Counselors (ABGC)



Completed Projects

- Genetic education for providers and patients through development of the following brochures, available through ATHN.org or by e-mailing Cathy Haupt (chaupt@athn.org)
 - Genetic Counseling for the Inherited Bleeding Disorders Community
 - Pre- and Post- genetic testing FAQs
- Identify available resources and post on the ATHN website
- Sponsored a booth at the 2014, 2015 National Society of Genetic Counselors (NSGC) Annual Education Conference



Future/Ongoing Projects

- Development of a Family Planning Guide for families with blood disorders.