

2018 NERGN Inaugural Meeting

Summary of Round Tables

04/05/18

Medical Round Table

- Outreach suggestions
 - On-call triage
 - Online resources
 - Pre-recorded webinars
 - Electronic health records – if there is a field or visual cue raises referral to genetics, that may be helpful
 - Ask the payers to serve the role of providing number for person to help triage – it’s in their interest
 - NCC is doing a Gene Dossier project to educate payers on why payment for diagnosis is needed; looking for people to collaborate
 - Early Intervention providers could be obvious place to add a question about referral to genetics; or have the reports reviewed routinely by appropriated entity before returned to parents
- Incorporating Genetics into Practice
 - Importance of Family History early on in the process, inclusive of social histories
 - Need for review of who is ordering genetic testing and efficacy rate
 - Need for overall guidance on when individuals should be referred for genetic services
 - Note challenge of who is available to serve referred patients
 - Note passiveness of system
 - *Need to include more than primary care, including social workers, community health, etc. Early Intervention would be good to include. Wants everyone to be “thinking genetically”*

Family Round Table

- What do they wish their providers knew about genetics?
 - Honesty on what is known / not known
 - Ability to cut through red tape and work the system
 - Ability to provide guidance on how a condition can affect other parts of their lives
 - Connections to family organizations
 - Need to balance appropriate roles for primary care
- GESS Feedback
 - Include resources for underserved populations and make it clear
 - Focus on newly diagnosed families who are looking for specific info on conditions;

CHW / Social Worker Round Table

- CHW is more of an umbrella term for peer support, peer recovery, etc.
- Limitations frequently tied to funding sources, some work with schools, others health teams, others may work more individually
- Opportunities to Collaborate:
 - Noted multiple training opportunities that we can integrate with, though currently limited opportunities around genetics
 - Regional group in NH that meets monthly
 - participate in development of regional and state plans
 - MA Patient Navigator Conference next year
 - Regional and national AHEC network
 - Paula Smith willing to collaborate with us, needs clarification on the roles we'd like to see CHWs take on
 - Training CHWs to appropriately recommend linkages to genetic counselors

Public Health Roundtable

- Critical that states look at genetics from public health perspective. Chronic disease, social determinants. Encourages NERGN to work with PH depts to think about including genetics. Incorporate into every aspect, not stand alone.
- In CT they do have a good system for referring newborns, but may have issue educating PCPs, nurses, data entry even (time of birth). People need to know why it is important.
- Which parts of the government can we identify and leverage related to public health and genetics?
- Importance of grassroots efforts (see Heartland example, mobile offices, improved community integration)
- Role of education
- Examples of specific challenges to pursue (e.g. ambulances which take patients only to the closest hospital)