

Meeting Minutes: Advisory Committee for Heritable and Congenital Disorders

October 9, 2018

Minutes prepared by: Jessica Cavazos, Newborn Screening Program Health Educator

Location: Wilder Center

Advisors Present

- Sue Berry
- Kristi Borowski
- Sheyhan Gelle
- Bob Jacobson
- Steve Johnson
- Amy Karger
- Jan Larson
- Kristin Loncorich
- Dieter Matern
- Steve Nelson
- Kiki Sarafoglou
- Emilee Scheid
- Renee Temme
- Jennifer Ward

Advisors Absent

- Vikas Bhambhani
- Jenny Jacobson
- Courtney Jarboe
- Annamarie Saarinen
- Kevin Sheridan
- Kathy Stagni

Summary of Decisions Made

- Decision: The April 17, 2018 meeting minutes were approved.

Agenda

- Welcome and Introductions
- Family Story – Sickle Cell Disease
 - Idara Uko – Shared his story as a father of 3 children, one of which has sickle cell disease (SCD). Shared they learned of their child's diagnosis through follow-up of their oldest child's trait status being identified. He discussed the pros and cons of early awareness and the parental impact of carrying a trait and the parental guilt associated with passing the disease to their child.
- Sickle Cell Disease (SCD) – Still Room for Improvement after 30 Years
 - Ms. Rae Blaylark – Shared the community perspective of SCD and the work of the Sickle Cell Foundation of Minnesota (SCFMN) to establish itself and identify the SCD community in Minnesota. She shared the work the SCFMN has been undertaking through community listening

sessions, to best identify the needs of the community. Ms. Blaylark shared patient stories and perspectives on the barriers to quality care that this community experiences.

- Dr. Steve Nelson – Shared the etiology, clinical manifestations, and treatment and management of SCD. He discussed how NBS has impacted the clinical course for SCD and the approach used by his team upon a new NBS diagnosis. Dr. Nelson described some of the main equity concerns that exist for this patient population and some of the on-going work that is currently occurring to address some of these disparities, but with still much work left to do. Dr. Nelson specifically discussed the need for improved long-term follow-up for SCD.
- Discussion:
 - There was agreement by some advisors that long term follow-up remains an area of improvement for all NBS disorders. Questions were asked about how things have changed for SCD over the past 25 years as a result of treatments, NBS, and the need to continue to focus on improving quality of life. There was discussion about the benefits to the CF community given how resourced they are and the ability to have an active and extensive registry, that does not exist, currently, for SCD. There was discussion about the impacts of racism and the opioid crisis on the SCD community. There was shared discussion of ways that this community can leverage the work of other disorders to develop emergency department guidelines and patient emergency plans.
- Disorder Nomination and Consideration Model Development
 - Steve Johnson and Maggie Dreon: reviewed the goals of the nomination process development work. Shared the two workgroups (advisors and community) as well as the timeline that this will be made available. Shared the takeaway information from the community engagement workgroup and the main highlights from the advisor workgroup.
- Committee Business
 - Review and Approval of April 2018 Meeting Minutes
 - Motion to approve minutes by Steve Johnson, Sue Berry second. Vote: all ayes, motion passes
 - Bylaws changes
 - Workgroup has begun reviewing the bylaws, however the Disorder Nomination process may impact the bylaws and therefore waiting for those to be completed is the most logical. Additionally, 30 days' notice on bylaw changes is required, therefore no voting will occur today.
 - Term expirations
 - An email will go out to advisors whose terms are expiring about their ability to reapply for the committee as half of the committee expires in January. MDH-wide efforts to ensure diversity is being considered in this process and the committee coordinators will be taken a broad approach to publicize the committee vacancies.
- Advisors Updates and Closure
 - Dr. Matern inquired about any recent nominations to the program. Maggie Dreon responded that as the disorder nomination process has been underway there have not been any formal nominations at this time.
 - Sue asked for an update on initial outcomes of recently added disorders.