

# Meeting Minutes: Advisory Committee for Heritable and Congenital Disorders

## October 15, 2019

Minutes prepared by: Amy Dahle, Newborn Screening Program Health Program Representative  
Location: Wilder Center

### Advisors Present

- Courtney Jarboe
- Amy Karger
- Bob Jacobson
- Teresa Rink
- Renee Temme
- Rachel Clark
- Steve Nelson
- Katie Pfister
- Steve Johnson
- Kevin Sheridan
- Jan Larson
- Peter Karachunski
- Sue Berry
- Sheyhan Gelle
- Annamarie Saarinen
- Rae Blaylark

### Advisors Absent

- Jennifer Arveson
- Kristi Borowski
- Cathy Long
- Dieter Matern
- Emilee Scheid
- Kathy Stagni
- Becca Williams

### Summary of Decisions Made

- Decision: The April 23, 2019 meeting minutes were approved.
- Decision: Committee adopted with one modification the work group revisions to their bylaws.

### Summary of Action Items

- Action/Assigned to/Due date
  - Further discussion on term limits is needed. Discussed perhaps coming back to this at the next meeting in April 2020.

## Agenda

- Welcome and Introductions
  - Mark gave a program update (new units, new testing contract with Mayo, QA report overview, and specialist annual summaries).
    - Asked the group if we make the QA reports and specialist annual summaries public. Sue wanted to discuss with her team, but suggested aggregate data for specialist summaries. Advisors discussed that the focus of sharing this data publicly should be about ways to improve.
- Committee Business
  - Approval of April 2019 meeting minutes
    - Annamarie mentioned that her and Sue were at a national meeting, that is why there were absent.
    - Approved, Steve J and Bob J second it. Motion carried.
  - Condition Nomination and Consideration Process – LIVE
    - New website is now live.
  - Term Expirations
    - Some committee members' terms are expiring, please reference your packet to see if you are one of them. Members are welcome to re-apply for another term.
  - Bylaws – discussion and vote
    - Work group members (Rachel Clark, Courtney Jarboe, Steve Johnson, Jan Larson, Dieter Matern, and Renee Temme) met on August 5<sup>th</sup> to discuss changes to make to the committee's bylaws and today those proposed changes were discussed and voted on.
    - Discussion:
      - Largely focused on the term limit proposal
        - Concern: rationale for term limits
        - Comment: keeps the group from becoming stagnate and to keep the committee with fresh faces
        - Concern: finding enough qualified specialists
        - Comment: we don't actually control the membership of the committee, it is the Commissioner of Health. The Commissioner can weigh in about who is on the committee.
        - Comment: there are room for exceptions.
        - Comment: suggest that current members on their way out can suggest people who can replace them.
        - Concern: how to deal with current membership with this in place; roll everyone off at once?
        - Comment: terms are dictated by statute with about half coterminous with governor and half the following year.
        - Comment: concern about losing specialists and suggest that statute categories C&F not be restricted to 2 terms
        - Comment: suggest taking out the term limits.

- Comment: suggest deferring until next meeting
  - Comment: a lot of organizations have term limits, but we want to make sure we do this right.
  - Discussion around how to re-word in the current bylaws in order to pass the rest of the proposed changes.
- Steering Committee
  - Question: who are the supervisors?
  - Comment: Operations supervisor (Jill Simonetti), Lab supervisors (Amy Hietala and Carrie Wolf), blood spot follow-up supervisor (was Amy Gaviglio but is yet to be filled), point of care follow-up supervisor (Jenna Laine), long-term follow-up supervisor (Nicole Brown).
  - Comment: steering committee all MDH staff except the chair and co-chair
- Decision Making Process
  - Clarification: “express any disagreements...”
  - Comment: steering committee will review and decide if it moves forward then let the full committee know. Disagreements can be brought up at that time if there is subject matter information known that would be helpful to know.
  - Concern: potential volume issue if there are multiple nominations
  - Comment: the advisory committee will still be involved and priority can be discussed
  - Clarification: is there a different process for conditions already added to the RUSP
  - Comment: Yes, there is an abbreviated process that removes a meeting and doesn’t require a work group review.
- Vote
  - Bob motioned to accept the bylaws as written with the following amendment: keep only the first sentence but strike the word “first”
  - Steve J seconded the motion
  - All ayes, no nays (motion carries)
- Public Health Long-term Follow-up
  - Summary of update: Nicole presented
    - What is long term follow-up? Why do it? Public health vs medicine. What is important to know? Expand PH LTFU.
    - Questions/comments:
      - Sue thanked Nicole’s team. Congratulated her on the sickle cell grant.
      - Bob congratulated her on her grants. And mentioned about the great opportunity to learn about sickle cell population that moves into MN.
- Congenital Cytomegalovirus (cCMV)
  - See slides
  - Discussion

- Rachel asked if there are any other benefits to start treatment for the asymptomatic.
    - There is no knowledge to support the benefit.
  - Sue asked about the regulatory status of drugs and mentioned that a lot of drugs are used for off label purposes.
    - No FDA approved antiviral for CMV; treatment is more management; not just medication.
  - Katie asked if there is a potential for a vaccine.
    - Challenge is you need something better than natural immunity. Likely 10-15 years out yet.
  - Peter asked about the long term outcomes of neuro-cognitive development. Peter mentioned he likely see kids in his clinic that he has worked up that have abnormal MRIs that are not very specific; likely might have had CMV.
  - Annamarie mentioned the CCHD doesn't have a prescribed treatment but guided by intervention and cCMV could be the same way, not prescriptive. "You are getting really close."
- Advisors Updates and Closure
  - Sue: NBS Save Lives Act is hung up. Sue encouraged members to contact your senators and agreed to send information to Sondra to disseminate to all members.
  - Annamarie: Hold up is due to some language (consent). No discretion committee. Re-authorization needs to go through.
  - Steve J motioned for closure, and Courtney second it. All ayes, no nays (motion carried).

## Next Meeting

Date: April 7, 2020

Time: 1-4 pm

Location: Wilder Center

Agenda items: submit proposed agenda items to Sondra Rosendahl [Sondra.Rosendahl@state.mn.us](mailto:Sondra.Rosendahl@state.mn.us)

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