

# Meeting Minutes: Advisory Committee for Heritable and Congenital Disorders

April 23, 2019

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

Location: Wilder Center

## Advisors Present

- Jennifer Arveson
- Rae Blaylark
- Kristi Borowski
- Rachel Clark
- Sheyhan Gelle
- Robert Jacobson
- Courtney Jarboe
- Steven Johnson
- Peter Karachunski
- Amy Karger
- Jan Larson
- Catherine Long
- Dietrich Matern
- Stephen Nelson
- Katie Pfister
- Teresa Rink
- Emilee Scheid
- Kevin Sheridan
- Kathy Stagni
- Renee Temme
- Becca Williams

## Advisors Absent

- Sue Berry
- Annamarie Saarinen

## Summary of Decisions Made

- Decision: The October 9, 2018 meeting minutes were approved.
- Decision: Committee adopted a new condition nomination and consideration process.
- Decision: Committee approved replacement of the committee's standing guidelines for condition consideration with newly developed guidelines and a condition readiness matrix.

## Summary of Action Items

- Action/Assigned to/Due date
  - Bylaws work group to meet before next meeting.

## Agenda

- Welcome and Introductions
  - Advisors briefly introduced themselves
- Committee Business
  - Approval of October 9, 2019 meeting minutes
    - Motion to approve minutes by Bob Jacobson, Steve Nelson second. Vote: all ayes, motion passes.
  - Bylaws—update on timeline
    - Bylaws changes have been put on hold until the new disorder consideration and nomination process is finalized since that information is included in the bylaws.
  - Legislative activity
    - Mark Mccann, Newborn Screening program manager gave a brief review of legislative activity around newborn screening in Minnesota
      - Activity mentioned at previous meetings
        - G6PD bill has expired
      - Current Activity
        - EHDI Advisory Committee (HF 910/SF 1021), bill would extend the committee to 2025 and add an additional position for a member from the State Academy for the Deaf
        - Advisory Council on Rare Diseases (HF 684/SF 973) has been bundled into the omnibus bill
- Condition Nomination and Consideration Model Development
  - Steve Johnson (Committee member) and Maggie Dreon (Committee coordinator)
  - Condition Nomination Process
    - Reviewed public submission form
  - Condition Readiness Criteria and Matrix
    - Each criteria section was reviewed and discussed with multiple edits made.
    - Minor edit to the matrix to clarify the percentage range in the investigative section.
  - Vote on committee's role
    - Steve Johnson motioned to “adopt the condition nomination process for condition consideration in which a three meeting process (NSAC Initial Committee Meeting, Condition Readiness Workgroup, and NSAC meeting with Condition Readiness Workgroup Report-out and vote) is used for conditions that have not been added to the RUSP, and an abbreviated process for conditions which have been added to the RUSP.”
      - Courtney Jarboe seconded, vote: ayes have it. Motion passes.
    - Steve Johnson motioned to “replace the NSAC’s standing guidelines for condition consideration, Guidelines for Determining Appropriate Target Conditions for Newborn Screening, with the newly developed guidelines, Condition Readiness Criteria for Addition to Minnesota’s Newborn Screening Panel and accompanying Condition Readiness Matrix.”

- Motion amended by Dieter Matern to clarify replacing the standing guidelines with the newly developed ones but with the changes discussed/decided upon.
- Emilee Scheid seconds, vote: ayes have it. Motion passes.
- Newborn Screening Metrics
  - Amy Gaviglio, Kirsten Coverstone, and Heather Pint
    - Data shared for all three parts of newborn screening (bloodspot, hearing, and heart)
- Public Health Long-term Follow-up
  - Nicole Brown, Long-term Follow-Up Manager
  - Due to time constraints, this presentation will be presented at the October 15, 2019 meeting
  - Stakeholder forums are coming in June, would love your participation and input, will be receiving an invite soon.
- Advisors Updates and Closure

## Next Meeting

Date: October 15, 2019

Time: 1-4 pm

Location: Wilder Center

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

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06/03/2019

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