

# Newborn Screening Advisory Committee Meeting

Meeting Minutes of Tuesday, April 26, 2016

1:00-4:00

Wilder Center

Auditorium A - B

451 Lexington Parkway North

Saint Paul, MN 55104

## Committee Members Present:

Roshini Araham	Kirsten Dummer	Jan Larson	Emilee Scheid
Mark Bergeron	Sheyhan Gelle	Dieter Matern	Kevin Sheridan
Susan Berry	Bob Jacobson	Steve Nelson	Kathy Stagni
Vikas Bhambhani	Courtney Jarboe	Martha Overby	Renee Temme
Kristi Borowski	Ed Jenkins	Annamarie Saarinen	Julie Thompson
	Amy Karger	Kiki Sarafoglou	Larson
	Terri Laguna		Jennifer Ward

## Committee Members Absent: (N = Notification that s/he would be absent)

Jenny Bock (N)	Steve Johnson (N)
Michael Nwaneri (N)	Kristin Loncorich

## Guest Speakers:

Ed Ehlinger, MD	Mark Schleiss, MD
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- 1) Welcome and Introduction
  - a. Jan Larson (Chair) welcomed Commissioner Dr. Ed Ehlinger
  - b. Each member introduced themselves, role, and discussed what they get from being involved (per request of Dr. Ehlinger)
- 2) Dr. Ed Ehlinger
  - a. Thanked committee for involvement and guidance
  - b. Discussed Health Equity and the triple aims of health equity
  - c. Discussed desire for the committee to continue to review emerging conditions and not to simply presume to add based on the ACHDNC.
- 3) Welcome and MDH update
  - a. Mark McCann, Manager of Newborn Screening Program, welcomed the Committee members and guests to the Newborn Screening Advisory Committee meeting and reviewed the committee package. He shared that the commissioner had accepted the Committee's recommendation for Pompe, MPS-1, and X-ALD to be added to the MN panel. He explained that MDH will be starting a work group to guide implementation of these conditions (tentative Jan 1, 2017 implementation date). Discussed that we will be seeking a fee increase to meet the demands of the new conditions, and shared that

work groups for looking at additional conditions that are possibly coming up or that require further review will continue.

- 4) Business of Committee
  - a. Review of minutes from April 2015. Jan called for motion to approve. Sue Berry motioned. Mark Bergeron seconded. No discussion. Vote: Ayes, motion carries.
  - b. October 2015 Minutes: Dieter Matern suggested a correction of Hunters Hope Meeting Task force is meeting in 2 weeks, rather than ACHDNC as indicated. Motion to approve with the correction made: Bob Jacobson, Second: Sue Berry, Vote: Ayes, motion passes.
- 5) Cytomegalovirus
  - a. Guest speaker - Mark Schleiss, MD, UMN Department of Pediatric Infectious disease.
  - b. Provided a comprehensive review of congenital cytomegalovirus (cCMV), clinical features, diagnostic work-up, available therapies. Discussed CMV in the context of newborn screening and described current initiatives, both out of state as well as within the state of MN.
- 6) ACHDNC Update
  - a. Dieter Matern
  - b. Discussed recent ACHDNC meeting to review some of the themes discussed on a national level such as implications of the Federal Policy for the Protection of Human Subjects Notice of Proposed Rulemaking for Newborn Screening, transition models from pediatric to adult health care, ongoing workgroups, subcommittees, and specifically long-term follow-up. Discussed DHHS secretary signing off on conditions MPS I and X-ALD. Discussed Mayo's experience with Krabbe screening for Kentucky. Discussed Hunter's Hope meeting from October 2015.
  - c. Annamarie inquired about the differences between false positive rates as described in presented slides. Dieter Matern explained his perspective and Mark McCann spoke on behalf of MDH's Newborn Screening Program to explain the bidding process and differing lab approaches, specifically PerkinElmer Genetic's repeat model.
- 7) Bylaws revision
  - a. Proposed amendment to bylaws altering language about who should be encouraged to hold position of chair and vice chair from parents of affected children, to any individual who is category 1 (Parents, Children and other consumers). Motion: Sue Berry, Second: Kristen Dummer, Vote: Jan (Chair) called for a vote Amendment passes, motion carries.
- 8) MDH Update
  - a. MN Committee Coordinators Updates by Maggie and Sondra was skipped to try and make up some lost time.
  - b. Jill Simonetti - Ops Unit update:
    - i. Discussed change to new LIMS. Discussed NewSteps 360 Grant to reduce manual entry needs for newborn screening.
  - c. Amy Hietala - Laboratory Update:
    - i. March of Dimes Grant to Improve Screening for CAH (2014). Conducting a 1-year pilot study and evaluate performance and cost effectiveness.
  - d. Patti Constant – Communication and Education Unit
    - i. Highlighted some projects and process changes, including MinneStories, hemoglobinopathy trait notification expansion, prenatal survey year 2, State

Fair 2016, digital advertising, provider education initiative, and desire for input from committee members to help us reach our audience.

- e) Amy Gaviglio - Short-term Follow-up:
  - a. CCHD protocol modifications and trainings, CCHD in NICU population, electronic reporting system, MNSCREEN as a specialized registry and implementation update, health disparities in Karen community, contingency planning for NBS, QA reports and timeliness, short-term's role with new conditions, informed consent engine, and access to medical food initiatives.
- f) Tony Steyermark – Long-term Follow-up
  - a. Expanding follow-up plans, transition from pediatric to adult clinics, CCHD long-term follow-up plans, teleaudiology project, changing of data elements collected to standardize to look for social determinants of health.

9) Closure

- a. Advisors update: Please email Maggie/Sondra or entire committee if you have any updates or things you'd like to share.
- b. Jan (committee Chair): asked for motion to adjourn; Bob Jacobson: motion; Second: Amy Karger; Ayes, passed. Meeting is adjourned.