

State Advisory Council
Hereditary and Congenital Disorders
Minutes
October 22, 2024
Online meeting

Members Present

Jamie Fraser, Chair
Robert Brosius, Vice Chair
John McGing
Gerald Raymond
Linda Chell
Sharon Dols

MDH Staff

Lauren Whiteman
Laportia Barrows
Monique Veney
Kevin Brown
Tatum Cox

Guests

Shannon Dixon
Mary Hackbarth-UMSOM
Ada Hamosh-John Hopkins
Rodney Hargraves-MDH lab

Members Absent

Michelle Smith
Delegate Terri Hill
David Myles

Ex-Officio Present

Mary Mussman
Christine Dorley
Robert Myers
Theresa Wavra

CALL TO ORDER

The meeting was called to order at 5:33 p.m. Chairperson Jamie Fraser shared the meeting ground rules (meeting etiquette) with the committee.

I. WELCOME & ROLL CALL

Laportia Barrows conducted the meeting roll call.

II. APPROVAL OF MINUTES

Draft meeting minutes were sent to the Committee prior to the meeting for review. Chairperson Fraser asked if there were any edits to be made, and edits were made. Gerald Raymond made a motion to approve amended minutes, which was seconded by Shannon Dixon. There were no opposing votes. The minutes were approved with edits.

III. MEMBERSHIP UPDATE

Laportia Barrows reported to the Committee that the Senate seat and two community seats are still vacant. Applications are being accepted. The Council held a roll-call vote for Gerald Raymond, who was nominated as Council Chair at the last Committee Meeting. The Council also held a roll-call vote for Robert Brosius, who was nominated as Council Vice Chair at the

last Committee Meeting. There was a unanimous vote for both positions. Congratulations to Gerald and Robert.

IV. OLD BUSINESS

Propose mandating that REM be available for all NBS conditions

- Chairperson Jamie Fraser revisited the NBS REM discussion, recommending that REM be available for all qualifying NBS conditions from 0-64 years of age.
 - There was discussion regarding writing a formal letter of recommendation to the Secretary.
 - A vote was held and approved.
 - Chairperson Jamie Fraser will take the lead in drafting the letter.

NBS brochure language and ICD code update

- Lauren Whiteman displayed the NBS information brochure language and ICD code context on the screen for the council's feedback.
 - Discussion included
 - Changing the outdated visuals and language
 - Making the brochure more specific and inclusive
 - The Committee held a roll-call vote to approve the updated language in the NBS information brochure. All were in favor.
 - The Council requested the final infographic upon completion.

V. NEW BUSINESS

Krabbe Leukodystrophy screening parameters

- Chairperson Jamie Fraser shared with the Council that legislation mandates a specific timeline for disorders added to the RUSP (Recommended Uniform Screening Panel).
 - Krabbe's additional legislative guidance was mentioned.
 - Mandate requirements, such as following the RUSP recommendations and additions for Krabbe disease, were mentioned.
 - Chairperson Fraser revisited the discussion on how far the Council wanted to go with surveillance on Krabbe disease.
 - The RUSP recommendation vote was very specific to early infantile Krabbe.
 - The Council members were sent a Krabbe disease document to review for clarification.
 - Council members discussed the document and cut-offs.
 - A draft will be available at the next meeting for Council review.

Up-to-date primary care providers

- Chairperson Jamie Fraser discussed that primary care providers are unaware of what is on the NBS (newborn screen).
 - Discussions included what can wait versus what is time-critical.
 - Ongoing continued education should be offered to providers because of the rarity of diseases on the NBS.
 - There were different opinions on whether or not this education should be mandatory.
 - The Council did not reach a consensus on providers receiving further education.

VI. UPDATES

- MCHB/NBS – Laportia Barrows announced to the Committee that The APHL (Association of Public Health Laboratories) site visit is scheduled for January 13-17, 2025. The follow-up program and the state lab are participating. They are all excited. Laportia mentioned their first webinar was conducted with 65-70 in attendance, which is available on our website for providers. They are currently working on a webinar geared towards providers on how to speak with families regarding their NBS results. The goal is to have quarterly webinars. An educational newsletter will be going out to providers soon.
- Laboratory: Christine Dorley informed the Council that all documentation had been submitted to the procurement office for their reagent contract, procuring reagents for Krabbe Disease. A decision was made to multiplex all the Lysosomal Storage Disorders (LSDs) together in testing using liquid chromatography-tandem mass spectrometry. This is awaiting approval. Validation may begin as early as January for Krabbe and the remaining LSDs that need to be revalidated using liquid chromatography-tandem mass spectrometry. Kevin Brown added that they are on target for implementing screening for GAMT. The GAMT disorder will be added to the panel in early December.

VII. FUTURE TOPICS

Ongoing continued training and education for providers about NBS.

VIII. NEXT MEETING DATE

December 10, 2024

IX. ADJOURNMENT

Gerald Raymond moved to adjourn the meeting, seconded by Robert Brosius.
The meeting adjourned at 6:22 pm.