

State Advisory Council
Hereditary and Congenital Disorders
Minutes
December 10, 2024
On-line meeting

Members Present

Gerald Raymond, Chair
Robert Brosius, Vice Chair
John McGing
Shannon Dixon
Linda Chell
David Myles

MDH Staff

Lauren Whiteman
Laportia Barrows
Monique Veney
Luz Del Valle Sanchez
Tatum Cox

Members Absent

Michelle Smith
Jamie Fraser
Delegate Terri Hill
Sharon Dols

Guests

Carol Greene-UMMS
Mary Hackbarth-UMSOM
Ada Hamosh-John Hopkins

Ex-Officio Present

Theresa Wavre
Christine Dorley

CALL TO ORDER

The meeting was called to order at 5:32 pm. Meeting ground rules (meeting etiquette) were shared with the committee by Chairperson Gerald Raymond.

I. WELCOME & ROLL CALL

Laportia Barrows conducted meeting roll call.

II. APPROVAL OF MINUTES

Draft meeting minutes were sent out to the Committee prior to meeting for review. Chairperson Raymond asked if there were any edits to be made and edits were made. Motion to approve amended minutes made by Vice Chair Robert Brosius and seconded by Shannon Dixon. No opposing votes. Minutes approved with edits.

III. MEMBERSHIP UPDATE

Laportia Barrows reported to the Committee that the Senate seat and the two community seats are still vacant. A response is still being awaited from the office that handles the Senate seat correspondence, and an application received for one community seat did not qualify because of affiliation.

IV. OLD BUSINESS

Propose mandating that REM be available for all NBS conditions

- o Chairperson Gerald Raymond will get an update from Jamie Fraser in her absence on the draft letter she was working on from the last meetings discussion.

- Recommending a draft letter to the secretary mandating actual coverage that is not covered was suggested and discussed.

Krabbe Leukodystrophy screening parameters draft

- Chairperson Gerald Raymond and Jamie Fraser were responsible for the draft.
 - The draft specifics were discussed.
 - The MD State Laboratory added their psychosine stance on the matter.

V. NEW BUSINESS

None at the time.

VI. UPDATES

- MCHB/NBS – Lauren Whiteman announced to the Committee that they are getting ready for their site visit with APHL (Association of Public Health Laboratories). They will share next month with the Council the findings and recommendations. Laportia Barrows added they will be doing quarterly educational webinars regarding any topics. She shared she would love for this information to be shared with providers, facilities and offices. Site visits will begin again as well Laportia mentioned. They just recently met with Mercy Medical Center. They presented their report card which they are drafting now for all facilities in Maryland to help improve the NBS process. A website will be available for providers to go to for information to be accessible. Partnering with local organizations and getting the word out what is available and underway.
- Laboratory – Christine Dorley informed the Council they have begun screening for GAMT. Validation of Krabbe disease should begin mid-January, early February 2025. Their targeted timeline is July 1, 2025. Christine also shared because they did an FDA modified procedure for GAMT, they will be monitoring cut offs closely. After evaluation, potential changes in the near future.

VII. FUTURE TOPICS

Chair Raymond suggested hearing about Metachromatic Leukodystrophy (MLD) in the future to be aware as it comes down the RUSP pipeline.

VIII. NEXT MEETING DATE

January 21, 2025

IX. ADJOURNMENT

John McGing moved to adjourn the meeting and seconded by Shannon Dixon.
All in favor. Meeting adjourned at 6:07 pm.