

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

Members Present

Jamie Fraser, Chair
Robert Brosius, Vice Chair
John McGing
Sharon Dols
David Myles
Gerald Raymond
Shannon Dixon
Linda Chell
Delegate Terri Hill

Members Absent

Michelle Smith

Ex-Officio Present

Robert Myers
Theresa Wavra
Christine Dorley
Mary Mussman

MDH Staff

Laportia Barrows
Monique Veney
Luz Del Valle Sanchez

Guest

Carol Greene, UMD
Fizza Majid
Erin Strovel- UMD
Ada Hamosh- JHU
Kayla Lin- MDH Intern
Mary Hackbath- UMSOM
Ben Smith
Rodney Hargrove- MDH lab

I. CALL TO ORDER

Meeting called to order at 5:35 pm. Meeting ground rules were shared with the committee by Chairperson Jamie Fraser.

II. ROLL CALL & INTRODUCTION

Laportia Barrows conducted the meeting roll call.

III. APPROVAL OF MINUTES

Draft meeting minutes from the June 11th meeting were shared with the Committee. Motion to approve the minutes with clarifications made by Robert Brosius and seconded by Delegate Terri Hill. No opposing votes. Minutes approved.

IV. MEMBERSHIP UPDATE

Chairperson Jamie Fraser briefly reintroduced to the Committee Dr. Christine Dorley, Director of the Division of Newborn and Childhood Screening and community member Linda Chell.

Chairperson Fraser announced to the Council the Senate seat is still vacant.

John McGing and Sharon Dols expired term nominations were explained to the Committee. Laportia Barrows will send out the nomination form to members interested or know of anyone interested to complete and submit. John and Sharon's positions are expired but they have agreed to retain their positions until seats can be filled.

Chairperson Fraser mentioned to the Council that it is time for nominations for the Chairperson and Vice Chair positions. The nomination process was explained as being slightly different. Chair Fraser made a motion to nominate Gerald Raymond for Chairperson and Delegate Terri Hill seconded it. Chair Fraser made a motion to nominate Robert Brosius for Vice Chair and Delegate Terri Hill seconded it. Nominations were closed.

V. OLD BUSINESS

Mandating REM (The Rare and Expensive Case Management)

- Chairperson Jamie Fraser mentioned the previous discussion of recommending that a proposal to the Secretary to mandate REM Medicaid be made available for all NBS (Newborn Screening) conditions.
 - The most recent ICD 10 codes for many disorders did not exist the last time the REM qualifying diagnosis list was updated.
 - All NBS primary or secondary diagnosis should be REM qualifying diagnosis.
 - A REM diagnosis list revision with ICD 10's was introduced to the Committee.
 - It was agreed that most of the new conditions are listed but raising the ages from 20 to 64 for eligibility for Medicaid was a proposed recommendation.
 - The Council discussed REM qualifying lifelong disorders.
 - Chairperson Fraser and Mary Mussman agreed to further review the most recent revised list to clarify some ICD codes. After a discussion, the Committee will be able to know what needs to be addressed. The focus is families that cannot afford private insurance and qualify for Medicaid should have options to have REM.

NBS brochure language

It was agreed to table discussion until Lauren Whiteman is in attendance.

VI. NEW BUSINESS

Krabbe Leukodystrophy screening parameters

- Chairperson Jamie Fraser shared with the Committee Secretary of Health and Human Services signed off on Krabbe and Leukodystrophy NBS with a specific set of limitations related to cut offs.
 - The goal per the early advocates and the discussion surrounding this decision were made regarding with respect to limit the number false positives.
 - Chair Fraser wanted to ask if voting members had any concerns about following the RUSP guidance and the Secretary's sign off on those perimeters before having further discussions or recommendations with the lab. This will still lead to some long term surveillance but that will probably help to narrow down the number of people that will need to be surveyed.
 - After discussion, a recommendation of a RUSP refresher before voting for any formal recommendations was agreed on. A thirty-page document was sent out to members for review for later voting purposes.

VII. 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 will be partnering in that.
- Laboratory – Dr. Christine Dorley shared with the Council that optimization of MS/MS has been completed and data collection for GAMT has been started. Hopefully it will go live by December 1, 2024.

VIII. FUTURE TOPICS

None currently.

IX. NEXT MEETING DATE

October 22, 2024

X. ADJOURNMENT

Delegate Terri Hill moved to adjourn the meeting and was seconded by Sharon Dols.
Meeting adjourned at 6:19 pm.