

**State Advisory Council
Hereditary and Congenital Disorders**

Minutes

June 11, 2024

On-line meeting

Members Present

Jamie Fraser, Chair
Robert Brosius, Vice Chair
John McGing
Sharon Dols
Delegate Terri Hill
Gerald Raymond

David Myles

Members Absent

Shannon Dixon
Michelle Smith

Ex-Officio Present

Theresa Wavra

MDH Staff

Lauren Whiteman
Laportia Barrows
Monique Veney
Stacy Taylor
Luz Del Valle Sanchez
Kevin Brown
Mary Mussman

Prakash Paudyal

Guest

Carol Greene, UMD
Mary Hackbarth, UMD
Allison Faila, CNMC Genetics
Ben Smith
Cynthia Carter
Kayla Lin

CALL TO ORDER

Meeting called to order at 5:48 pm. Meeting ground rules were shared with the committee by Chairperson Jamie Fraser.

I. ROLL CALL & INTRODUCTION

Laportia Barrows conducted the meeting roll call.

II. APPROVAL OF MINUTES

Draft meeting minutes from the April 2nd meeting were sent out to the Committee prior to the meeting for review. Motion to approve minutes made by Robert Brosius and seconded by John McGing. No opposing votes. Minutes approved.

III. MEMBERSHIP UPDATE

Laportia Barrows reported to the Committee she has been informed that the letter for the Senate Seat has been sent up to the Secretary awaiting approval to have seat filled. An application for Dominique Sessa's seat is being followed up on.

IV. OLD BUSINESS

Council Priorities: Enabling Statutes: Health-General §13–108

- Topics from 4/2/24
 - The Committee touched further on 3 major pillars of their priorities that were discussed at the last meeting.
 - Priorities beyond Newborn Screening (NBS) are a primary focus of the Council.
 - Lauren Whiteman mentioned to the Committee as far as equity and education, Maryland Department of Health has a program within the Administration that goes by the name of Root Causes of Health Initiative and the project focuses on looking at data and identifying ways to look more deeply into health equity. The Council is interested in more information on this program. Lauren will have a presentation provided for the Council.
 - Coverage of medical food and formula is difficult. The status for State Medicaid at the REAM level versus other MCO's would be nice to know.
 - It was suggested that after diagnosis are picked up, they need to be treated. Those diseases need to be covered for diagnosis survey management.
 - The Committee discussed diagnosed children being able to benefit from NBS and being able to access treatment.
 - It was agreed that a mechanism should be in place to ensure children diagnosed have access to treatment.
 - Legislature support was discussed for this diagnosis.

V. NEW BUSINESS

Newborn Screening Educational Materials

- Lauren Whiteman presented to the Council the Office of Children and Youth with Specific Health Care Needs Newborn Screening (NBS) educational materials for provider's and families.
 - Getting more information out during pregnancy on NBS is the goal of the material.
 - The infographics were shared with the Committee and explained.
 - Work in progress to ensure all material is health literate and accessible. Edits are being drafted and recommendations are being accepted. Changes/updates will be made.
 - Final drafts will be shared with the Council.

VI. UPDATES

- MCHB/NBS Follow-up – Lauren Whiteman shared with the Committee updates being worked on and the new interns working on the offices website as well as creating brief explainer videos. The videos will be general information on NBS for families and providers offering information and providing tips to providers on blood spot screening processes.
- Lauren informed the Council that they are engaging with the APHL (Association of Public Health Laboratories) and they are coming out to do a free site visit spending a few days looking at the follow up program. They will review and provide suggestions and recommendations for the program. Lauren shared this should take place in the late summer and a summary will be provided to the Committee after the visit. Prakash Paudyal mentioned there has been discussion that the Maryland State Laboratory will be a part of the site visit as well.
- Laboratory – Prakash Paudyal shared with the Council the validating process for MPS II is going on and they are hoping to make it live by the end of next month.

VII. FUTURE TOPICS

- Prenatal Congenital issues.

- How can the council assist with these issues?

VIII. NEXT MEETING DATE

August 20, 2024

IX. ADJOURNMENT

Gerald Raymond moved to adjourn the meeting and was seconded by Delegate Terri Hill.
Meeting adjourned at 6:49 pm.