

**State Advisory Council  
Hereditary and Congenital Disorders**

**Minutes**

**April 2, 2024**

On-line meeting

**Members Present**

Jamie Fraser, Chair  
Robert Brosius, Vice Chair  
John McGing  
Michelle Smith  
Shannon Dixon  
Gerald Raymond

**MDH Staff**

Lauren Whiteman  
Monique Veney  
Luz Del Valle Sanchez  
Kevin Brown  
Prakash Paudyal  
Rodney Hargraves

**Members Absent**

David Myles  
Delegate Terri Hill  
Sharon Dols

**Guest**

Carol Greene, UMD  
Shelly Choo, MDH  
Ada Hamosh  
Erin Strovel, UMD  
Allison Faila  
Fizza Majid

**Ex-Officio Present**

Robert Myers  
Theresa Wavra

**CALL TO ORDER**

Meeting called to order at 5:50 pm. Meeting ground rules were shared with the committee by Chairperson Jamie Fraser.

**I. ROLL CALL & INTRODUCTION**

Lauren Whiteman conducted the meeting roll call.

**II. APPROVAL OF MINUTES**

Draft meeting minutes from the February 13th and the February 21st meetings were shared with the Committee. Motion to approve the minutes with edits made by John McGing and seconded by Shannon Dixon. No opposing votes. Minutes approved.

**III. MEMBERSHIP UPDATE**

Lauren Whiteman reported to the Committee two vacant seats currently. The Senator has resigned and The MDH Office of Appointments and Executive Nominations is currently outreaching to the President of the Senates office to try to get a replacement. Dominique Sessa's seat is vacant, and Lauren gave the stipulations for that seat and made a link to the application through the MDH appointments office available for anyone interested or knows of someone.

**IV. OLD BUSINESS**

## Senate Bill 0117/House Bill 0096 Health- Newborn Screening Program- Implementation of Testing

- o Lauren Whitman informed the Committee the House HGO voted favorably with the amendments.

### Status of MPS II and GAMT Letters

- o Prakash Paudyal shared that the letters were signed off on by the Secretary and will announce steps and timelines soon.

## V. NEW BUSINESS

### Council Priorities

- o The Councils priorities considering the recent legislative changes deserve revisiting because the Committee has a lot of opportunities to do good things to help families.
  - Chairperson Jamie Fraser shared on the screen the founding Legislation and Lauren Whiteman shared the link in the chat for the Committee to review.
  - The Council went over the Legislative articles.
  - Ideas of what to work on together as a Council were proposed.
  - Restriction reimbursements, medical foods and formula coverage were concerns raised.
  - Proposed mandating insurance and REM qualified conditions were discussed.
  - The Committee discussed medical disease coverage. Any child diagnosed should have REM or be ensured their insurance company pays their medical care.
  - Focusing on education and equity were points discussed. Reaching out to parent support groups.
  - MDH is actively working on educating and getting information out regarding all the different Newborn Screening follow up.
  - Next steps were a question and discussed.
  - It was agreed among the Council that priority would play a major part.

## VI. UPDATES

- MCHB/NBS – Lauren Whiteman shared with the Council education pieces her office has been working on. They are planning to get a summer student to help with doing explainer videos such as how to properly do a heel stick among other videos for their website for families and providers. Lauren also mentioned they are working on some updated infographics for families and providers as well and will share with the Committee for feedback.
- Laboratory – The lab reported to the Committee they are working on thalassemia for MPS II and GMAT and working on sending out samples for MPS I second tier tests to MAYO.

## VII. FUTURE TOPICS

Review list of Council priorities and rank those priorities.

## VIII. NEXT MEETING DATE

June 11, 2024

**IX. ADJOURNMENT**

Michelle Smith moved to adjourn the meeting and was seconded by John McGing.  
Meeting adjourned at 6:47 pm.