

**State Advisory Council  
Hereditary and Congenital Disorders  
Minutes (Draft)**

**January 9, 2024**

On-line meeting

**Members Present**

Jamie Fraser, Chair  
Robert Brosius, Vice Chair  
John McGing  
Sharon Dols  
Shannon Dixon  
Gerald Raymond

**Members Absent**

Senator Johnny Ray Salling  
Michelle Smith  
Delegate Terri Hill  
Dominique Sessa  
David Myles

**Ex-Officio Present**

Robert Myers

**MDH Staff**

Lauren Whiteman  
Laportia Barrows  
Monique Veney  
Theresa Wavra  
Luz Del Valle Sanchez  
Kevin Brown  
Prakash Paudyal  
Rodney Hargraves

**Guest**

Carol Greene, UMD  
Erin Strovel, UMD  
Paul Vetter  
Mary Hackbarth, UMD  
Jody Sheely, MDH  
Allison Faila, CNMC Genetics  
Fizza Majid  
Ada Hamosh  
Sofia Ayala

**CALL TO ORDER**

Meeting called to order at 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 December 5<sup>th</sup> meeting were sent out to the Committee prior to the meeting for review. Motion to approve minutes made by Shannon Dixon and seconded by Gerald Raymond. No opposing votes. Minutes approved.

**III. MEMBERSHIP UPDATE**

Lauren Whiteman reported to the Committee no membership updates at this time.

**IV. NEW BUSINESS**

Krabbe Leukodystrophy NBS SB0117/HB0096 Discussion

- Jody Sheely of the MDH, Office of Support Services discussed with the Committee the Krabbe Leukodystrophy addition to the Newborn Screening Program SB0117 and HB0096.
  - The bills were co-filed in the Senate and the House.
  - Krabbe would be added to the existing NBS panel.
  - Either bill has been scheduled for hearing yet but hearing in the Committee would be the first official opportunity for the Council to officially weigh in or for individual private citizens to do so by providing either written or in person testimony.
  - It was suggested to the Council to meet with one or both of the sponsors to provide them with some background as to how historically conditions have been added to the panel.
- The Council was explained the back story of Krabbe.
- Drafting of a Krabbe position statement was discussed among the Council.
  - An email draft will be sent out to Council voting members for feedback.
  - Depending on the timeline of the session, members may need to be called back to vote on the position statement.
  - Council members will need to meet to officially approve the position statement within 24-48 hours.
  - The Council was reminded of key components of the position statement. Focus only on the process and the only thing to be put in writing.
  - The Committee was instructed to plan to go testify.
  - Jody Sheely informed the Committee that filing of fiscal note request was just received from the Senate so the bill most likely will be scheduled soon.
  - In addition to writing the letter, it was suggested to the Committee to move and meet with the chairs of both the House and Senate Committees to let them know what the opposition is.
  - Council members agreed to work on the draft letter. The Council was instructed to check emails often and they will receive draft letter from Lauren Whiteman for review and feedback.

Concerns of accessioning delay discussion among the Council.

## **V. OLD BUSINESS**

Status of MPS II letter

- Lauren Whiteman informed the Council the letter has gone to MDH Office of Governmental Affairs. Additional information needed to be prepared that was requested. The Secretary has not signed off yet. Lauren will provide regular updates to the Committee until official word.

Status of X-ALD

- X Adrenoleukodystrophy screening is onboard and rolling out. It was done before originally expected.

## **VI. UPDATES**

- MCHB – Lauren Whiteman announced to the Committee of her offices new name which is now the Office for Children and Youth with Specific Health Care Needs.

- Laboratory – Dr. Myers announced they have a list of candidates for Dr. Majids vacated Division Chiefs position. There are three or four viable candidates. Interviews will be held by the end of the month.
- NBS Follow-up- Lauren informed the Council during Laportia's maternity leave, the follow up program will be overseen and covered by Office for Children and Youth with Specific Health Care Needs staff.

## **VII. FUTURE TOPICS**

Quality control issues. Point of contacts can be Dr. Myers, Dr. Prakash and/or Kevin Brown for follow up investigations to find out exactly the source of the problem(s).

## **VIII. NEXT MEETING DATE**

February 6, 2024

## **IX. ADJOURNMENT**

John McGing moved to adjourn the meeting and was seconded by Sharon Dols .  
Meeting adjourned at pm.

**State Advisory Council**  
**Hereditary and Congenital Disorders**  
**Ad hoc Meeting Minutes (Draft)**

**January 31, 2024**

On-line meeting

**Members Present**

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

David Myles

**Members Absent**

Michelle Smith  
Senator Johnny Ray Salling

**Ex-Officio Present**

Robert Myers

**MDH Staff**

Lauren Whiteman  
Theresa Wavra  
Monique Veney  
Rodney Hargraves  
Luz Del Valle Sanchez  
Prakash Paudyal

**Guest**

Carol Greene, UMD  
Erin Strovel, UMD  
Paul Vetter  
  
Mary Hackbarth, UMD

**I. ROLL CALL & INTRODUCTION**

Lauren Whiteman conducted the meeting roll call.

**II. UPDATE OF KRABBE STATUS**

Chairperson Jamie Fraser gave a summary of the Krabbe addition to the Newborn Screening Program SB and HB. January 30<sup>th</sup>, the HRSA Advisory Council held a vote to specifically add Krabbe to the NBS.

- Council members received drafted letters to the Chair of the House of Delegates and the Senate Chair.
- Council members discussed the position statement drafted letters.
- Edits to the date of the letters were made. Otherwise, the letters were agreed upon.
- Motion to approve drafted letters with revisions was made by John McGing and seconded by Gerald Raymond.
- A roll call vote was unanimous to accept letters as drafted.
- The submission process of drafted letters was discussed amongst the Council.
- In person testimony was discussed.

**III. NEXT MEETING DATE**

February 13, 2024

**IV. ADJOURNMENT**

Sharon Dols moved to adjourn the meeting and was seconded by Delegate Terri Hill.

Meeting adjourned.

**State Advisory Council**  
**Hereditary and Congenital Disorders**  
**Minutes**

**February 13, 2024**

Virtual meeting

**Members Present**

Jamie Fraser, Chair  
Robert Brosius, Vice Chair  
John McGing  
Sharon Dols  
David Myles  
Gerald Raymond

**Members Absent**

Shannon Dixon  
Michelle Smith  
Delegate Terri Hill

**Ex-Officio Present**

Robert Myers  
Theresa Wavra

**MDH Staff**

Lauren Whiteman  
Stacy Taylor  
Monique Veney  
Jody Sheely  
Luz Del Valle Sanchez  
Kevin Brown  
Prakash Paudyal  
Rodney Hargraves

**Guest**

Carol Greene, UMD  
Ada Hamosh  
Paul Vetter  
Mary Hackbarth, UMD  
Dr. K  
Shelly Choo, MDH  
Joseph Orsini NY Labs  
Barbrara Burton - Lurie  
Joanna Kurtzberg Duke  
Ali Fatemi – KKI  
Anna Grantham - HH  
Eric Mallek- KKI  
Matthew Nikzad UMD  
Matthew Fairchild- UMD  
Jasmine Maghari- UMD  
Erin Strovel- UMD

**CALL TO ORDER**

Meeting called to order at 5:34 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 January 9<sup>th</sup> meeting were shared with the Committee.  
Motion to approve the minutes with edits made by Gerald Raymond and seconded by Sharon Dols. No opposing votes. Minutes approved.

### **III. MEMBERSHIP UPDATE**

Lauren Whiteman reported to the Committee that Senator Johnny Ray Salling and Dominique Sessa has resigned from their positions. Lauren mentioned the open seat position is posted through the MDH appointments and nominations office on their website to apply and she asked the Committee if any specific organizations anyone would like for her to reach out to for that seat. The MDH Office of Appointments and Nominations has reached out to the Senate office to seek another Senator.

### **IV. OLD BUSINESS**

- Status of Letters
  - MPS II
    - Lauren Whiteman announced to the Committee the letter is still under review and has been submitted through the process. A memo has been drafted to accompany the letter.
  - GAMT
    - Lauren Whiteman announced to the Committee the letter is still under review and has been submitted through the process. A memo has been drafted to accompany the letter.
  - SB0117/HB0096 Health – Newborn Screening Program – Krabbe Leukodystrophy
    - Chairperson Jamie Fraser shared that letters have been voted on and signed through appropriate channels. She testified

### **V. NEW BUSINESS**

- Review of Recent Advisory Committee on Heritable Disorders in Newborns and Children
  - Chairperson Jamie Fraser shared overviews of presentations, information
    - “Families’ search for meaning and value in rare genetic diagnoses”- Sara Ackerman, UCSF
    - PDFs on the RUSP website
      - “Forecast for the Future. A story about Genetic Testing”
    - “Family Outcomes of Newborn Screening: Project Background and Overview
    - ACHDNC’s “Decision Matrix Tool: Public Health Impact Assessment”
    - “Recommendations to the ACHDNC for Newborn Screening of Krabbe Disease”
      - Liaison’s Guidance Based on Evidence Review
        - Moderate certainty the screening would have a significant benefit
        - Infantile Krabbe disease, as defined by low GALC enzyme activity and psychosine  $\geq 10$  nM is NOT recommended for inclusion as a core condition on the RUSP
        - Members voted 10-3 in favor of the addition to the RUSP
        - The recommendation goes to the Secretary of HHS
- Review of draft plan following HHS Secretary's Approval
  - 30, 60, 90 & 120 days timeline
  - Expert speakers will be asked to provide their credentials, affiliations, disclosure of funding sources, and peer-reviewed sources in advance of their presentation

- Speakers will be asked to provide their presentations in advance to the voting members of the committee
- All data must be published in final form in a peer-reviewed journal
- Draft letter to be sent out to voting members for review/edits
- John McGing and Ada Hamosh shared concerns about adding Krabbe outside of the committee's normal process
- Kathleen Smith shared concerns about Krabbe not being included in Maryland's newborn screening despite previous attempts

#### **VI. UPDATES**

- MCHB/NBS – No updates at this time.
- Laboratory – Dr. Myers reported to the Committee two positive ALD results since adding to the RUSP in January.

#### **VII. FUTURE TOPICS**

Duchenne Muscular Dystrophy

#### **VIII. NEXT MEETING DATE**

February 21, 2024

#### **IX. ADJOURNMENT**

Gerald Raymond moved to adjourn the meeting and was seconded by John McGing. The meeting adjourned at 6:57 pm.



**State Advisory Council  
Hereditary and Congenital Disorders  
Minutes**

**February 21, 2024**

On-line meeting

**Members Present**

Jamie Fraser, Chair  
Robert Brosius, Vice Chair  
John McGing  
Sharon Dols  
David Myles  
Gerald Raymond  
Shannon Dixon  
Michelle Smith

**Members Absent**

Delegate Terri Hill

**MDH Staff**

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

**Guest**

**Ex-Officio Present**

Robert Myers  
Theresa Wavra  
Mary Mussman

**CALL TO ORDER**

Meeting called to order at 5:3 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. OLD BUSINESS**

Motion to approve letter to HGO by David Myles, and seconded by John McGing. Motion approved.

Motion to approve letter to Senate Finance Chair by John McGing, Shannon Dixon seconded. Motion approved.

**III. NEXT MEETING DATE**

Two meetings scheduled: March 5, 2024 (if needed) and April 2, 2024

**IV. ADJOURNMENT**

Motion to adjourn by Michelle Smith and seconded by Sharon Dols at 5:49pm.

**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.

**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 2<sup>nd</sup> 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.

**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 11<sup>th</sup> 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)

- o 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

- o 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.

**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.

**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

**Members Absent**

Michelle Smith  
Jamie Fraser  
Delegate Terri Hill  
Sharon Dols

**Ex-Officio Present**

Theresa Wavre  
Christine Dorley

**MDH Staff**

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

**Guests**

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

**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

- o 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.