

**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.
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  - 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.