**State Advisory Council**

**Hereditary and Congenital Disorders**

**Minutes (Draft)**

**January 9, 2024**

On-line meeting

**Members Present** **MDH Staff**

Jamie Fraser, Chair Lauren Whiteman

Robert Brosius, Vice Chair Laportia Barrows

John McGing Monique Veney

Sharon Dols Theresa Wavra

Shannon Dixon Luz Del Valle Sanchez

Gerald Raymond Kevin Brown

Prakash Paudyal

Rodney Hargraves

**Members Absent**

Senator Johnny Ray Salling **Guest**

Michelle Smith Carol Greene, UMD

Delegate Terri Hill Erin Strovel, UMD

Dominque Sessa Paul Vetter

David Myles Mary Hackbarth, UMD

Jody Sheely, MDH

**Ex-Officio Present** Allison Faila, CNMC Genetics

Robert Myers 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 5th 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 overseed 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.