

State Advisory Council
Hereditary and Congenital Disorders
Minutes (Draft)
January 21, 2025
On-line meeting

Members Present

Gerald Raymond, Chair
Robert Brosius, Vice Chair
John McGing
Shannon Dixon
Delegate Terri Hill
Sharon Dols
Linda Chell
David Myles

Members Absent

Ex-Officio Present

Christine Dorley
Mary Mussman
Robert Myers

MDH Staff

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

Guests

Carol Greene, UMMS
Mary Hackbarth, UMSOM
Fizza Majid
Rodney Hargraves, MDH lab

CALLED TO ORDER

Meeting called to order at 5:33 pm. Meeting ground rules (meeting etiquette) were shared with the Council by Chairperson Gerald Raymond.

I. WELCOME & ROLL CALL

Laportia Barrows conducted the 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 comments. Motion to approve minutes made by Shannon Dixon and seconded by John McGing. No opposing votes. Minutes approved.

III. MEMBERSHIP UPDATE

Laportia Barrows reported to the Council that the Senate seat is still vacant. There are also three lay person vacant seats open. She asked that members pass the word out and she will share the application link for those interested in applying. MDH also has a brief explanation of the Council and obligations available for anyone to look at if they have any questions of the Council.

IV. OLD BUSINESS

Propose mandating that REM be available for all NBS conditions

- o Chairperson Raymond revisited the discussion from a few meetings ago and asked Council if they had any recollection and/or input.
 - The original idea was discussed.
 - There was discussion regarding the REM list.
 - It was mentioned that a proposal letter had begun being drafted and that will be looked into further.
 - It was shared that the Rare Disease Council has some REM conditions interests as well and a good idea for the Committee to align with them.
 - Some Council agreed to attend the upcoming Rare Disease Council meeting.

Krabbe Leukodystrophy screening parameters draft

- o The Krabbe draft letter was displayed on the screen for the Council to view.
 - Chairperson Raymond gave the Council the background and goals of the letter. He asked that the letter be reviewed for input.
 - The Committee discussed the letter and made suggestions and edits.
 - Motion to approve the letter made by John McGing and seconded by Delegate Terri Hill. A vote was held to approve the letter. No opposing votes. Letter approved.

MLD in the RUSP pipeline

- o Chairperson Raymond informed the Committee that he reached out to a speaker and will have them do an MLD presentation at the next meeting.

Effects of genetic counselor billing

- o After reaching out to a few colleagues across the States, Shannan Dixon reported to the Council that no one has reported any major challenges. She will keep the Committee updated on any changes she comes across.

V. NEW BUSINESS

None

VI. UPDATES

- MCHB – Lauren Whiteman shared with the Council their review went very well. An abbreviated report will be available in about 6 weeks and the full report in 3-4 months. Once they are received, she will share the findings with the Committee. Lauren also shared that they are continuing working on their educational tools. They are working on an aggravate report to share with the group and asked for feedback on their orientation packet that had been sent out.
- Laboratory – Christine Dorley reported to the Committee that the lab is progressing with the validation of Krabbe. They have been receiving what is needed. A technical rep. from Revati will be coming the first week of February for optimization. Test runs will be run. The validation study will begin shortly after. July 1st is the target date to begin.

VII. FUTURE TOPICS

Metachromatic leukodystrophy (MLD) speaker.

VIII. NEXT MEETING DATE

March 25, 2025, 5:30 pm

IX. ADJOURNMENT

Sharon Dols moved to adjourn the meeting and seconded by Vice Chair Robert Brosius. Meeting adjourned at 6:12 pm.