

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

March 2, 2022 5:30 PM
(Virtual meeting secondary to Covid-19)

Members Present

Erin Strovel, Chair
Jamie Fraser, Vice Chair
Robert Brosius
Jamie Fraser
Sharon Dols
Meral Gunay
John McGing

Members Absent

David Myles
Senator Edward Reilly
Delegate Karen Lewis-Young
Michelle Smith
1 vacant health unrelated position

Ex-Officio Present

Johnna Watson
Stacy Taylor

Ex-Officio Absent

Fizza Majid
Robert Myers

Guests

Ada Hamosh, Hopkins Genetics
Carol Greene, UMMS Genetics
Shelly Choo, MCHB, MD
Paul Vetter, PerkinElmer Genetics

MDH Staff

Monique Veney
Laportia Barrows

I. WELCOME & ROLL CALL

Roll call completed and quorum present.

Dr. Strovel, Council Chair, welcomed everyone to the meeting.

II. LEGISLATIVE UPDATE

Dr. Strovel shared current proposed amendments to HB 109 that were recently discussed between her and Delegate Shetty. Changes in current proposed amendments were reviewed.

Clarification is needed on when the two-year time period begins - either after the condition is on the RUSP or the Maryland newborn screening panel -was discussed. The name of the Council in incorrect in the Bill. Suggested changes to the name of the Council and clarification regarding the 2-year time period were entered into the document with track changes to share back with Delegate Shetty.

Dr. Strovel received an email during this meeting from Delegate Shetty indicating she is meeting with the advocates tomorrow. The Council does not feel a letter of support should be given until proposed amendments are finalized since there are still discussions with the advocates.

Letter of support was edited to reflect support of the current proposed amendments in anticipation of submission after the Delegate's meeting with the advocates, with the addition of the name change and the timeframe starting after the condition has been approved by the Secretary of Health for inclusion on the Maryland newborn screening panel.

Motion made by Dr. Fraser to approve the letter of support as written now, unless there are significant changes to the amendments, after Delegate Shetty meets with the advocates. Motion seconded by John McGing. Roll call vote taken with 6 yes and 0 no votes. Motion was also made by Dr Fraser to allow staff to make any technical changes necessary to the letter. Motion seconded by John McGing and approved.

Planned tentative meeting currently set for 3/3/2022 will remain scheduled pending response from the advocates. Dr. Fraser also recommended that future meetings be planned for every month or every other month to keep on track with the timeline.

Dr. Strovel will communicate the suggested changes and request the bill version from Delegate Shetty and forward the letter. John McGing motioned to adjourn and Dr. Fraser seconded.

Meeting adjourned at 7:01 PM