**State Advisory Council**

**Hereditary and Congenital Disorders**

**Ad hoc Meeting Minutes (Draft)**

**January 31, 2024**

On-line meeting

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

Jamie Fraser, Chair Lauren Whiteman

Robert Brosius, Vice Chair Theresa Wavra

John McGing Monique Veney

Sharon Dols Rodney Hargraves

Shannon Dixon Luz Del Valle Sanchez

Gerald Raymond Prakash Paudyal

Delegate Terri Hill

**Guest**

David Myles Carol Greene, UMD

Erin Strovel, UMD

**Members Absent** Paul Vetter

Michelle Smith

Senator Johnny Ray Salling Mary Hackbarth, UMD

**Ex-Officio Present**

Robert Myers

**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 30th, 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.