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

**Minutes August 18, 2020**

(Virtual meeting secondary to Covid-19)

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

John McGing, Chair Monique Veney

Michelle Smith LaPortia Barrows

Hilary Vernon

David Myles **Ex-Officio Present**

Delegate Karen Lewis-Young Johnna Watson (scribe)

Erin Strovel Stacy Taylor

Robert Brosius Fizza Majid

Senator Edward Reilly Robert Myers

Jamie Frazer

**Members Absent** **Guests**

Marjorie Shulbank Paul Vetter

Ben Smith Carol Greene

**Called to Order** – 5:05 pm

**I. WELCOME**

John McGing, Council Chair, extended a welcome to all attendees. In virtual meeting environment introductions around the table were not conducted. However, attendees attending by phone were identified.

**II. APPROVAL OF MINUTES**

Minutes from meeting on April 21, 2020, were approved and will be posted on website.

**III. MEMBERSHIP UPDATES**

Johnna Watson reported there is only one current vacancy for a Health Unrelated Member. Ben Smith’s term expired in June of 2020. However, Ben Smith (absent for this meeting) agreed at the April meeting to remain on the Council until a replacement has been identified for his Council position.

John McGing also addressed the vacant Vice Chair position which was discussed at the last meeting in April, 2020. Erin Strovel agreed at this meeting to serve as Vice Chair for this Council.

**IV. OLD BUSINESS**

Update regarding letters to Secretary

* Johnna Watson reports it was determined through an internal discussion conducted by Jed Miller and personnel in Medicaid that the billing codes included in the draft of the letter were incorrect. Dan Shattuck representing the Coalition for Access to Prenatal Screening emailed the correct billing codes just this afternoon. John McGing states the letter will be updated and distributed again to the Council members for a short period of review, if it is changed substantively, prior to forwarding to the Secretary.
* John McGing asked about the status of the second letter which was supposed to be drafted by Ben Smith in support of hiring new staff for the newborn screening laboratory so implementation of X-ALD screening could begin. Ben Smith is not present at this meeting for an update. The letter was supposed to be shared with the Council prior to it being sent so most likely has not been drafted. The status of the letter needs to be determined.

**V. MCHB UPDATES** (Stacy Taylor, Deputy Director, OGPSHCN)

* Deputy Secretary Fran Phillips has retired and Dr. Jinlene Chan is now serving as Acting Deputy Secretary for Public Health.
* Dr. Shelly Choo has been appointed as new Medical Director for Maternal and Child Health Bureau. Dr. Choo is coming from the Baltimore City Department of Health.
* LaPortia Barrows was introduced as the new nurse consultant with the Newborn Screening Follow-up Program. Johnna Watson gave a brief background of LaPortia’s experience and the challenges of training a new nurse while everyone is working remotely during the COVID-19 pandemic.

**VIII. LABORATORY UPDATES**

* Dr. Myers reports there is a regulation change to add the new screens onto the screening panel.
* He also reports that there will be a post-doctoral fellow in the laboratory starting in September.
* Johnna Watson reports that the lab has added DNA for cystic fibrosis to the newborn screening process. DNA will automatically be performed on the 1st specimen if IRT is very high. Otherwise, it will be IRT/IRT and then DNA if the second IRT remains above the cut-off. All babies with one mutation are being referred for sweat chloride testing at this time. Dr. Greene asked if referral rate for sweat chloride testing has increased with the new DNA protocol. Johnna Watson reports there does not appear to be an observed increase at this time to the referral rate but since it has only been in place for a couple of months it is hard to determine at this time. Dr. Greene also asked what is happening with babies who have 2 IRTs and no mutations found. Johnna Watson reports she will have to discuss with Dr. Majid since this situation has not been reported for follow-up currently.
* No update at this time for X-ALD implementation. Dr. Myers reports that Dr. Majid was working on cost analysis the last time he spoke with her, but he has not seen any information recently that he can share.

**IX. NEXT MEETING DATE**

* John McGing proposed meeting again in December. Due to holidays, December 8th was selected for the next meeting date. No conflicts with professional meetings were identified, but meeting date can be shifted if needed.

**X. ADJOURNMENT**

 Meeting adjourned 5:30 PM