

State Advisory Council on Hereditary and Congenital Disorders

Minutes January 5, 2021

(Virtual meeting secondary to Covid-19)

Members Present

John McGing, Chair
Ben Smith
Hilary Vernon
David Myles
Jamie Fraser
Erin Strovel
Senator Edward Reilly

Members Absent

Marjorie Shulbank
Michelle Smith
Delegate Karen Lewis-Young
Robert Brosius

MDH Staff

Monique Veney
LaPortia Barrows

Ex-Officio Present

Johnna Watson (scribe)
Stacy Taylor
Fizza Majid
Robert Myers

Guests

Carol Greene
Danielle Pantalone, Cullari Communications

Called to Order – 5:04 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 August 18, 2020 were approved and will be posted on website.

III. MEMBERSHIP UPDATES

- Johnna Watson reported Delegate Karen Lewis Young has asked to be taken off of this committee so a new delegate member will be sought.
- One health unrelated member position is open. Johnna received an email from someone interested in that position so an application will be sent out to them,

IV. OLD BUSINESS

- Letter re. genetic testing techniques not covered by Medicaid.
 - Johnna Watson reported that the letter has been completed and released to the secretary.
- Letter re. hiring new staff for the newborn screening laboratory to perform X-ALD screening
 - Discussion between Ben Smith and Dr. Majid about need for letter and details of need. Ben asked about a hiring freeze. Dr. Majid stated the lab has not received any new PIN's for positions at this time. The lab is down 5 positions and recruitment has been taking a while, but these positions are for regular lab operations, not for adding X-ALD screening. Ben asked if the letter should address the wider issue of manning the entire lab instead of just addressing staffing for testing of one disorder. Dr. Majid thinks the focus of the letter should be addressing the additional staff needed for X-ALD.
 - Ben will begin drafting this particular letter to be sent out to the committee for review.
 - Question from Jamie Fraser asking if staffing issues are why there is still no 2nd tier testing for MPS-1. Dr. Majid indicates development of 2nd tier testing is very

challenging when all positions are not filled. Staffing is needed to implement XALD and then the lab can start looking at 2nd tier testing, not only for MPS-I, but others as well. Erin Strovel states UMMS Biochemical lab is also having trouble hiring, particularly since private labs can pay higher.

V. UPDATES

MCHB

- Stacy Taylor reports Secretary Neal retired effective Dec. 1, 2020.
- Dennis Schrader is now the Acting Secretary who has been in this role in the past.
- Dr. Jinlene Chan is still serving as Acting Deputy Secretary for Public Health, which was the role Fran Phillips held before her retirement.
- There no specific updates on Covid-19 related matters, but just be aware there is a significant impact to all of our staff. We are not specifically involved in any of the vaccine issues, but Governor Hogan is holding a press conference currently about the vaccine updates so everyone is welcome to check out the summary after this meeting.

Laboratory

- Fizza Majid reports the lab is currently trying to keep up with the work due to staff shortage and no new PIN's. Discussion ensued about whether or not the State can increase pay to hire and keep staff. Decisions related to increasing pay are at a higher level within the State.
- Robert Myers alluded to the tremendous amount of Covid work being done by the lab. Specimen volume is 10,000 specimens a week, as opposed to normally 7,000 specimens weekly. There is a lot of sequencing work also happening with Covid to identify variants and a lot of staff is being pulled into this testing.
- Robert Myers further states that Dr. Majid is trying to acquire the mass spectrometers needed to implement X-ALD. The reserve fund may need to be tapped for this procurement, and after that, a fee increase may need to be asked for. An analysis will be done to see. The lab is trying to hire staff, but the job market for lab science people is pretty competitive now.

Newborn Screening Symposium

- Fizza Majid shared that she was able to attend part of the Symposium which focused on:
 - increasing second tier testing and sequencing
 - changing shifts around due to Covid so that Newborn Screening does not shut down because of concerns.
- Johnna Watson reports that NBS Follow-up had a workshop with other Follow-up units across the country and most teams are operating remotely successfully.

Advisory Committee on Heritable Disorders in Newborns & Children

- Johnna Watson shared that the meeting was held on December 1, 2020 and the committee is reviewing their processes on how they are scoring new conditions.

VI. Future Topics for Discussion

- Johnna Watson would like to review process for adding conditions to the Maryland newborn screening panel. Hilary Vernon and Erin Strovel will give a presentation at the next meeting regarding the criteria that was developed by a sub-committee of this council for adding conditions.
- Funding for the laboratory was brought up by David Myles. Further discussion ensued regarding funding for the laboratory and whether or not the Council should be involved with asking for more funding, particularly to add 2nd tier testing. John McGing recapped at the end of the discussion the need to address current issues and processes. Ben Smith will work on a letter to make a position statement on the need to hire staff to begin implementation of X-ALD screening. He hopes to have a draft within a week.
- John mentioned if any further topics for discussions come up, they can be submitted to Johnna, and they will be added to the agenda.

- Ben Smith asked for a presentation from Dr. Myles to see how the military handles newborn screening across different states. Discussion ensued regarding there are not only differences between military babies across the world but also between states which is the reason that the Federal Advisory Council has developed the recommended universal screening panel (RUSP) which creates a baseline that all states should include in their panels.

VII. NEXT MEETING DATE

April 20, 2021

VIII. ADJOURNMENT

John McGing moved to adjourn. Motion seconded by Jamie Fraser.
Meeting adjourned 5:56 PM