

State Advisory Council on Hereditary and Congenital Disorders

Minutes April 21, 2020

(Virtual meeting secondary to Covid-19)

Members Present

John McGing, Chair
Michelle Smith
Hilary Vernon
Delegate Karen Lewis-Young
Erin Strovel
Jamie Fraser
Ben Smith
David Myles
Robert Brosius
Senator Edward Reilly

Members Absent

Marjorie Shulbank

MDH Staff

Monique Veney

Ex-Officio Present

Johnna Watson (scribe)
Stacy Taylor
Fizza Majid

Guests

Paul Vetter
Carol Greene
Hannah Baer
Dan Shattuck
Mimi Blitzer

Called to Order – 5:10 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, given there are 4 new members, the agenda was altered to allow earlier introductions of the newest members.

- Senator Edward Reilly is the new Maryland Senate representative - 11th year in the Maryland Senate, represents the 13th District, which is central Anne Arundel County, Member of the Finance Committee; retired sales agent for Nationwide insurance
- Jamie Fraser, MD - Biochemical geneticist at Children's National Medical Center, replacing Sarah Viall on the Council. She is a Charles County resident and has been in Maryland since 2010.
- Robert Brosius - works in a small school in Baltimore City, background is in biology and has interests in other sciences. Has been a Maryland resident for about 10 years and attended Loyola University.
- Fourth new member, Marjorie Shulbank, was unable to attend tonight's meeting

II. APPROVAL OF MINUTES

Minutes from meeting on October, 2019, were approved and will be posted on website.

III. INTRODUCTIONS OF NEW MEMBERS

This agenda item was addressed during the welcoming remarks.

IV: MEMBERSHIP UPDATES

Membership Update

- Johnna Watson reported that Ben Smith's term is expiring as of June 1st, 2020. She asked if he would be willing to continue to serve on the Council until a replacement is determined. Ben Smith stated he would be willing to stay on the Council in the interim.
- John McGing brought up the need for a vice chair for the Council. John states it is his impression that if there is a consumer chair than there should be a professional vice chair so there is a progression of experience of both consumer and professional representatives serving as chair. Dr. Carol Greene stated she thought Erin Strovel would be a good choice for vice chair who has a lot of experience with how the committee works. John McGing did not want to put Dr. Strovel on the spot tonight but encouraged her to think about being vice chair.

V. NEW BUSINESS:

Discussion of Covid-19 and effects upon newborn screening in Maryland & nationally

- Johnna Watson reports that NBS Follow-Up personnel are all working remotely and lab staff are working 1 week on and 2 weeks off.
- Data entry staff is also rotating working in the office and working remotely. Staff is teleworking as much as possible while still maintaining the newborn screening process as much as possible.
- Senator Reilly asked where the lab is located and Johnna Watson reports that it is located in Baltimore City near the Johns Hopkins medical campus. He asked what kind of testing is done at the lab. Johnna Watson explained that all testing done by the Maryland State Laboratory is performed at this location. However, the discussion as pertaining to this Council is focused on newborn screening. A brief description of newborn screening was given. Typically, every baby is screened at 24 hours of age and 24 hours of feeding and again at about 2 weeks of age for over 50 metabolic conditions.
- Fizza Majid, newborn screening laboratory director, reports they are meeting turnaround times for the most part. It seems that babies are being discharged earlier so the number of specimens collected at less than 24 hours is increasing. Difficult to work with 1/3 of staff and analytical evaluation is mostly off site.
- Johnna Watson reports that some provider offices have altered their hours or closed their offices which makes it more difficult to contact them to report abnormal results and/or to obtain repeat newborn screening specimens as needed.

VI. OLD BUSINESS

Update regarding information presented by Coalition for Access to Prenatal Screening (CAPS)

- John McGing recapped presentation by CAPS and the request for support to send a letter to have Maryland Medicaid pay for this prenatal testing. He states he has not been able to find out Maryland Medicaid's position on this issue.
- Jamie Fraser states her experience indicates that no genetic testing is covered through Maryland Medicaid. John McGing states that he does not feel there is enough known about Maryland Medicaid's position to craft a letter that would be meaningful to address this issue.
- Jamie Fraser states she has pursued this area of questioning with Maryland Medicaid in the past regarding all genetic testing and she does not feel it should be limited to just this prenatal screening. If the Council is going to write a letter in support of Medicaid paying for testing, the letter should include all genetic testing and not just this prenatal screening.
- John McGing reiterated that is why we need to know what is happening in Medicaid so any letter would be have value.

- Ben Smith asked if the Council has been able to obtain Medicaid's position to which John McGing says we have not been able to find out any information about their position.
- Ben Smith asks what would it hurt to craft a position letter in support of this prenatal screening stating the letter could create the dialog to start the discussion within Medicaid.
- Hannah Baer from CAPS states that Maryland Medicaid has a policy that was adapted in 2017 which is a high risk only policy indicating that MD Medicaid is covering it for one part of the population but not for everyone. As of 2 years ago, MD Medicaid decided to maintain their high risk only policy.
- John McGing states he has been waiting to hear back from MDH (specifically Jed Miller) who was going to reach out to Medicaid to see if their policy has changed and he would like to know the facts before writing the letter.
- Stacy Taylor, deputy director for OGPSHCN, states Dr. Miller has reached out to Medicaid but has yet to receive a response. His stance at this point, in lieu of a response from Medicaid, is that a letter from the Council may push it up a notch on Medicaid's priority list.
- Ben Smith asked what if a letter was drafted asking on the stance of the Department.
- Stacy Taylor indicates this action appears appropriate at this time.
- Dr. Carol Greene indicates she would be willing to assist in drafting this letter.
- Jamie Fraser asked what prenatally screening CAPS is currently focusing on. Hannah Baer answered the screening is currently focused on Trisomy 13, 18 and 21.
- John McGing asked if Carol would be willing to start the letter and she indicates she is better at editing so John will start the letter
- The letter will be sent out to the Council for review once it has been drafted.
- Motion made that Chair will work on letter and seconded. No one opposed.

VII. MCHB UPDATES

- Stacy Taylor gave an update on the organizational chart within MDH
- Governor has issued a hiring freeze currently
- Sickle Cell Disease Steering Committee has reconvened
- Johnna Watson announced that Linda Lammeree is retiring in a couple of weeks

VIII. LABORATORY UPDATES

- Fizza Majid reports that the hiring freeze may affect X-ALD implementation.
- Condition approve by Secretary about 2 years ago but positions have been frozen and unfrozen several times over the past 2 years.
- This condition also requires a capital investment of 2 new mass spectrometry machines
- Ben Smith asks if a letter from the Council to the Governor's office help with the hiring freeze.
- Dr, Majid states they are looking at positions on a case by case basis to determine if hiring freezes can be lifted.
- Jamie Fraser states she has examples of cases that could be used in writing a letter supporting hiring of state for x-ald implementation.
- Ben Smith thinks it would be helpful to have a letter written.
- John McGing affirmed that the letter should be written to the Secretary and not to the Governor's office.
- Ben Smith moved that a letter be written to the Secretary to request an exception to the hiring freeze. Vote was unanimous.
- Ben Smith and Jamie Fraser will work on the letter.

- Letter is to be sent to the Council for review and Ben Smith put a time limit of 4 weeks on the drafting of the letter.
- Robert Brosius asked if the Council was in need of any grant funding or help with applying for grants. Johnna Watson states there are no grants that this Council is not directly involved with any grants.
- Ben Smith asked for assistance in obtaining a new research article that discusses Krabbe. Dr. Fraser states that with time she should be able to obtain the article.

IX. NEXT MEETING DATE

- Ben Smith wants to meet in July instead of October. Dr. Fraser asked if the meeting could be pushed to August or later.
- Dr. Greene asked if the platform could be changed from Google Meets to Zoom. Johnna Watson states there is a limitation with platforms that can be used and Zoom is not allowed.
- John McGing proposed August 18th for the next meeting date.

X. ADJOURNMENT

Meeting adjourned 6:08 PM

State Advisory Council on Hereditary and Congenital Disorders

Minutes August 18, 2020

(Virtual meeting secondary to Covid-19)

Members Present

John McGing, Chair
Michelle Smith
Hilary Vernon
David Myles
Delegate Karen Lewis-Young
Erin Strovel
Robert Brosius
Senator Edward Reilly
Jamie Frazer

MDH Staff

Monique Veney
LaPortia Barrows

Ex-Officio Present

Johnna Watson (scribe)
Stacy Taylor
Fizza Majid
Robert Myers

Members Absent

Marjorie Shulbank
Ben Smith

Guests

Paul Vetter
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