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

**Minutes June 12, 2018**

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

Hilary Vernon, MD, Chair Linda Lammeree (Scribe)

John McGing, Vice Chair Jed Miller, MD

Erin Strovel, PhD

Rebecca Furman (phone)

Anne Eder **Guests**

Michelle Smith (phone) Sarah Viall, CNMC Genetics (phone)

Paul Vetter, (phone)

**Members Absent**

Ben Smith

Neil Porter, MD

Delegate Karen Young

Senator Ronald Young

David Myles, MD

**Ex-Officio Present**

Fizza Majid, PhD (phone)

Johnna Watson

**Called to Order** – 5:31 pm

**I. Welcome and Introductions**

* Quorum not present at beginning of meeting so meeting delayed until quorum present.
* While waiting for quorum to be reached, Sarah Viall, CNMC Genetics discussed recent phone call with Maryland Medicaid re: billing codes for genetic testing. A miscommunication has occurred with some MCO’s and is being clarified. Sarah stated she will send email to Dr Vernon containing billing codes that should be covered so that information can be shared with UMMS Genetics and JHH Genetics.

**II. Minutes of Meeting**

* Minutes of Advisory Council meeting April 17, 2018 were approved.

**III. Old Business**

* Discussion of Maryland Medicaid coverage for pediatric genetic counseling

1. In preparation for this meeting, Dr. Vernon forwarded to Advisory Council members for their review a draft of a letter to Mr. Dennis Schrader, Chief Operating Officer &Director of Medicaid, recommending inclusion of pediatric genetic counselors as practitioners.
2. Written comments were submitted by Dr. Carol Greene, Ms. Rebecca Furman and Dr. Lee Woods and forwarded to Dr. Vernon.
3. Dr. Vernon will revise the letter and forward it to Advisory Council members for their review.
4. Due to importance of concern and in interest of timeliness, a motion was made and seconded that barring objections, revised letter will be sent to Mr Schrader and Secretary of Maryland Department of Health, Mr. Neall. Date for objections to be forwarded to Dr. Vernon is July 12, 2018.
5. Motion approved.

**IV. Member Updates**

* Laboratory Administration

1. Dr. Majid, Director of Newborn Screening Lab, reported no significant change from April 2018 meeting update. Procurement and personnel efforts continue and at this time there is not a timetable for start of testing for the new conditions.
2. Dr. Majid stated that the newborn screening lab is experiencing a higher than usual vacancy rate. Goal is to continue to report abnormal results on time.

* MCHB

1. Dr. Jed Miller, Director of Office for Genetics and People with Special Healthcare Needs, provided update on SB105 that changes the membership of the Advisory Council and the appointment process. The bill was signed by the governor 05/15/2018 and will take effect 07/01/2018.
2. SB105 removed a member seat for an agency that is no longer in existence (State Health Planning and Development Agency) and also removed the seat formerly assigned to Monumental Medical Society.
3. The bill created a seat for Children’s National Medical Center (CNMC).
4. All members of the Advisory Council, both voting and non-voting, will be appointed by the Maryland Secretary of Health.
5. Dr. Miller also reported that the Maternal Child Health Bureau has a new Director, Michael Spencer as of 06/06/2018. Prior to joining the MDH, Mr. Spencer was with the Health Resources and Services Administration serving as a Title V MCH Block Grant project officer, providing oversight and technical assistance to State grantees implementing their MCH and Children and Youth with Special Health Care Needs initiatives.
6. Johnna Watson, Chief Newborn Screening Follow up Unit stated that the (Federal) Advisory Committee on Heritable Disorders in Newborns and Children met on May 9 and May 10, 2018.
   1. Sarah Viall, CNMC Genetics attended the meeting and stated no new votes took place .
   2. That there is no response to date from the Health Secretary re: inclusion of SMA to RUSP
   3. Education work group is designing a one page educational sheet using mnemonic SCREEN to help providers speak with families re: abnormal results.
   4. d. Dissemination of that educational sheet is under discussion. Maryland NBS may be interested in sending it out to providers.

**V. Meeting schedule**

* The Advisory Committee is required by statute to meet at least twice a year.
* It was discussed and agreed that meetings will be the second Tuesday of October and April, making dates of next meetings October 9, 2018 and April 9, 2019.
* John McGing, chair as of 07/01/2018, stated he hopes this stability will help ensure a quorum is present to promote timely conduct of council business.
* Other meetings can be added at needed.
* Anne Eder, aware that her second term expires 08/13/2018, questioned if she can continue to attend and vote until her replacement is approved. Dr. Miller stated that the statute for the Advisory Council states that members can continue on the Committee until their successor is appointed.

**VI. Adjournment**

Meeting adjourned at 5:56 PM.