

# State Advisory Council on Hereditary and Congenital Disorders

Minutes April 5, 2016

## Members Present

Anne Eder, Chair  
John McGing  
Senator Ronald N Young (phone)  
Neil Porter, MD  
Erin Strovel, PhD  
Delegate Karen Lewis Young (phone)  
Dr. Richard Bruno

## Staff

Linda Lammeree, RN, (Scribe)  
Tina Wiegand

## Ex-Officio Present

Robert Myers, PhD  
Fizza Majid, PhD  
Johnna Watson, RN

## Members Absent

Ben Smith  
Hilary Vernon, MD

## Guests

Jennifer Payne  
Amanda Janson

## Called to Order – 5:10 pm

### I. Welcome and Introductions

- Members and guests introduced themselves.
- New member, Dr. Richard Bruno, introduced himself as a resident with interest in combined areas of primary care and preventive care. He fills the Med Chi vacancy.

### II. Meeting Minutes January 12, 2016

- Anne Eder, Chair, stated that voting on the minutes from the January 12th meeting would be delayed until quorum was present. Johnna Watson reported that a correction to the minutes is needed: Dr. Woods is an ex-officio member of the Advisory Council.

### III. New Business

#### A. Medical Foods

- Anne Eder introduced Jennifer Payne who detailed for the Council her experiences and difficulties obtaining insurance coverage for the medically necessary foods required to treat the genetic disorder of Phenylketonuria (PKU). These difficulties are due in part to changes in the labeling and classification of these products. Phenylketonuria, which is a condition on the newborn screening, requires a special diet.
- Several members of the Advisory Council acknowledged that they are not certain what, if any, role the Advisory Council can adopt in this issue. The members expressed appreciation to Ms. Payne for bringing the matter to their attention and enabling them to learn more about conditions identified by newborn screening that require special infant formulas and, later in life, medically necessary foods.

#### B. Membership Update

- Anne Eder stated that the terms of several Council members expire as of 06/30/2016 including:
  - ✓ Dr. Porter, representative of Monumental City Medical group who is not eligible for another term given he has served 2 terms. Johnna Watson reports a letter has been written to Monumental City Medical asking for candidates. Dr. Porter was also asked if he knew of any members of Monumental City Medical that may be interested in joining the Council. Although due to decreased membership in that group, it may be necessary to consider approaching other professional organizations dedicated to representing and advocating for the needs of underserved populations. Since this particular position is

specified in the make-up of the council, it may be necessary to change the council bylaws.

- ✓ Two health unrelated positions also expire- those currently held by John McGing and Ben Smith. Both members are eligible to apply for another term.
- ✓ Johnna Watson summarized a meeting with the Governor's appointment specialist. It was determined that the Council needs to explore ways to recruit members that will add more variety as well as geographical and ethnic diversity to the Advisory Council.
- ✓ Anne Eder stated that although her term continues, her position as Chair is expiring. This highlights the need for a Vice Chair who can move seamlessly into the position of Chair when the Chair's term expires. Currently, no one on the Council holds the Vice Chair position.
- ✓ Anne asked that members let her know if anyone is interested in assuming the roles of Chair and Vice-Chair.

#### **IV. Old Business**

##### **A. Federal Contingency Plan**

- Johnna Watson stated that the Federal contingency plan is being finalized. It is a very broad plan encouraging each state to assess barriers to practice and develop procedures to ensure continuation of work, i.e. how newborn screen specimens will be received, processed, screened, and reported in the event of significant emergency.
- Dr. Myers stated that the lab has handshake agreements with neighboring programs in the event an emergency prevents the lab from operating.

##### **B. Scoring Tool**

- Anne thanked Dr. Porter who configured the scoring tool to auto-calculate the score. This is a great time saver.
- Anne also stated that perhaps sometime in the coming year, a work group could help make the tool more "lay member" friendly.

##### **C. Legislative issues of 2016 Maryland General Assembly**

- House Bill 827- sponsored by Delegate O'Donnell- As originally introduced, would have enabled parents to request newborn screening from a laboratory other than the State laboratory. The bill was amended and passed the House and Senate. As enacted, it requires DHMH's Newborn Screening Program to notify parents/guardians of newborn infants that laboratories other than DHMH's public health laboratory are authorized to perform post-screening confirmatory or diagnostic tests on newborn infants for hereditary and congenital disorders.
- House Bill 4692- Aiden's Law- mandates state to screen for X-ALD with inclusion of time frame for implementation. This bill was introduced March 3<sup>rd</sup> in House and Senate. It was referred to House Energy and Commerce Committee and then referred to Subcommittee on Health.
- House Bill 1392 (*Medical Laboratories – Direct-to-Consumer Genetic Testing*) would have authorized laboratories to market direct-to-consumer genetic testing in Maryland. The bill was introduced several years ago and opposed by the physician community. The bill received an unfavorable vote by the House Health and Government Operations Committee.

##### **D. Member updates**

- Dr. Majid, Newborn Screen Lab Director, stated that SCID (severe combined immunodeficiency) screening went live on 04/01/2016 with three days of results obtained and reports in the process of being generated. Dr. Majid has received approval to approach UMBC for MIPAR (contractual) employees, since additional staff members are needed to complete SCID screening. Providers were notified by website and memo about addition of SCID screening to the panel.
- Maternal Child Health Bureau-NBS Follow up - Johnna Watson, Chief of NBS Follow-up Unit, reported that Dr. Badawi, who served as Medical Director for NBS Follow-up, has resigned effective February. NBS follow-up nurses are asked to contact the genetics centers should situations develop beyond scope of nursing practice. Protocols will be reviewed systematically to help reduce any ambiguities.

#### **V. 2016 Meeting Schedule**

- Next meeting dates are:  
June 7, 2016  
September 6, 2016  
December 6, 2016

#### **VI. Adjournment**

- Prior to adjournment, Anne stated that a quorum was present due to arrival of additional members after the start of the meeting. Therefore it was possible to vote on the minutes from the January meeting.
- John McGing made a motion to accept the minutes with correction. Motion seconded by Erin Strovel. Minutes accepted by vote of members present.
- Meeting adjourned at 6:30 pm.