

State Advisory Council on Hereditary and Congenital Disorders

Minutes February 3, 2015

Members Present

Anne Eder, Chair
Aaron Kauffman (phone)
Hilary Vernon, MD
Ben Smith (phone)
Neil Porter, MD
Sandra Takai, MD (phone)

Members Absent

Delegate Shirley Nathan-Pulliam
Coleen Giofredda
Erin Strovel, PhD
Caryl Siems

Ex-Officio Present

Deborah Badawi, MD
Robert Myers, PhD
Fizza Majid, PhD
Lee Woods, MD

Staff

Johnna Watson, RN (scribe)
Linda Lammeree, RN
Hilda Castillo, PhD
Tina Wiegand

Guests

John McGing
Sarah Viall (phone)
Ada Hamosh, MD (phone)
Carol Greene, MD (phone)
S. Daniel Leydorf, medical student
Sarah Viall, NP (phone)

Called to Order – 6:00 pm

I. Welcome and Introductions

Anne Eder welcomed members and guests. Members and guests introduced themselves.

II. Approval of January 2015 Minutes

Minutes reviewed and approved with correction to Dr. Castillo's credentials.

III. New Business

- Anne Eder reports that some members will be late to the meeting so voting for inclusion of Fabry Disease in Maryland newborn screening panel will take place after discussion of new business
- **Legislative Updates**
 - Anne Eder reports that hearing was held in House subcommittee regarding HB 5, allowing money from newborn screening fees to return directly to newborn screening instead of the general fund. Anne testified in support of the bill. Aaron Kauffman was also present at the hearing in support of the bill. Department of Budget and Management testified against the bill. Anne and Aaron both relate positive feedback regarding passage of the bill. Ben Smith also relates speaking to Delegate O'Donnell who also feels bill will pass and there is bipartisan support for it. Anne reports bill is currently filed as an emergency bill for fast enactment but she is not sure if it will stay as an emergency or not. Implementation date may be delayed if does not stay as an emergency.
 - Dr. Badawi reports on SB 156 Sickle Cell Disease Outreach Program. Bill is very broad in scope requiring DHMH to coordinate with community to provide education, social support services and any other resources need to reduce acute care services for both adults and children. DHMH is opposing secondary to scope being unclear. DHMH is in the process of writing up a fiscal note because money was not included in the bill.
- **Member Updates**
 - Laboratories Administration
 - Dr. Myers reports the lab has ordered equipment for SCID testing but not received. Pilot testing will begin after the move to the new laboratory. Building has been turned over to the lab in January. Move to new facility will be in April and May.
 - OGPSHCN

- Dr. Badawi reports OGPSHCN continues to work with the laboratory to formulate follow-up protocols for SCID.
 - Member Updates
 - Anne Eder reports the application for John McGing to be a member of the Council has been submitted and is pending. She also reports the House of Delegates is working on proposing a Delegate to serve on the Council. At this time there is no movement in the Senate to provide a member.
- **Strategy for New Disorders**
 - Dr. Badawi reminded the Council that the lysosomal storage disorders will be reviewed annually to determine if new information is available to evaluate whether or not they should be included in newborn screening. Typical process of nomination of condition for consideration for inclusion in newborn screening is through one of the Council members or the laboratory itself.
 - Since multiple disorders have been reviewed in the past year, Dr. Badawi asked for feedback regarding process.
 - Dr. Vernon thinks process went well.
 - Mr. Smith feels voting was based on feelings and not information. He thinks the 2009 Assessing New Criteria for Newborn Screening by Botkin should have been used in review of the disorders. Dr. Vernon indicates that she included these criteria in her presentation.
 - Dr. Takai feels presentations were excellent and there was enough time to review information prior to voting. She feels voting was based on information presented.
 - Mr. Smith thinks lysosomal disorders should be looked at individually and not lumped together. Dr. Badawi indicates the presentation of information was separate and voting occurred separately for each condition.
 - Mr. Smith feels the grading scale from Botkin's article should have been used for each disorder.
 - Dr. Greene indicates the Botkin paper is now out of date. On the Federal level, the advisory committee has made changes to how disorders are looked at for consideration.
 - Dr. Badawi states the Council could assign a grade using a scoring tool in the future. Dr. Takai requests a copy of the most recent criteria for review to be disseminated to the Council members. Mr. Kauffman requests articles in plainer language and agrees to a grading process.
 - Anne Eder states the Council will look at how decisions are made. She feels presentations were outstanding and voting has been scientifically sound.

IV. Old Business

- **Voting for Inclusion of Fabry Disease**
 - Anne Eder asks if any further discussion regarding Fabry Disease is needed. No comment from council members. Move to vote on adding Fabry Disease to the Maryland RUSP was moved and seconded.
 - Voting initiated by roll call and results noted as follows:
 - Ben Smith – yea
 - Dr. Sandra Takai – yea
 - Dr. Hilary Vernon – yea
 - Anne Eder – yea
 - Dr. Neil Porter – yea
 - Aaron Kaufman – yea
 - Inclusion of Fabry Disease in the Maryland NBS RUSP is recommended at this time by a vote of 6 to 0 and no abstentions.
 - Dr. Badawi indicates next step is to send a letter to the Secretary regarding this recommendation.
 - Mr. Smith wants to review all of the disorders again. If screening for 2 of the disorders, then all of the disorders should be screened for.
 - Dr. Badawi stated that voting was based on scientific information and available treatments for each of the disorders. Anne Eder reiterates the discussion of lysosomal disorders will be revisited on an annual basis.

V. Next Meeting

- March 10, 2015 is being held for a possible date for the next meeting in case anything comes up in the legislative session. If not needed, next meeting will be June 2nd.
- June 2, 2015
- Sept 1, 2015
- Dec 1, 2015.

VI. Adjournment

- Meeting adjourned at 6:45 PM.