

CVAB Members Present

Voting Members

- Linda Burghardt
 Karen Calhoun
 Denise Chrysler
 Susan Dendrinis
 Rosalyn Beene Harris

- Tedra Jackson
 Joyce Kornbluh
 Neil MacVicar
 *Mary Lou Mason
 Ella Greene-Moton

- **Tressa Orthmeyer
 Stephen Rapundalo
 Tina Reynolds
 Thomas Rich
 Rita Walters

CVAB Designees

- *John Roy Castillo
 **Peggy Rush

Community Attendees: E. Hill De Loney, Yvonne Lewis, Ann Mongoven, Ariel Brovont

MDCH Staff: Carrie Langbo

1. Welcome and Introductions... Tedra Jackson

- T. Jackson welcomed board members and guests. Introductions were made. Quorum established.

2. Review of February 3, 2014 Minutes

- Minutes approved (motion by T. Jackson and N. MacVicar). Posted on BioTrust website (www.michigan.gov/biotrust).
- 4th Revision of Operating Policies and Procedures passed via electronic vote. Please see attached.

3. CVAB Updates

- Education and Outreach:** 9 events have taken place in 2014 to increase awareness about the BioTrust and parental options. Two events coordinated by N. MacVicar with the Michigan Health and Hospital Association, one event by K. Calhoun and an additional event by T. Jackson. MDCH is also working with S. Rapundalo on an article for inclusion in MichBio's next newsletter. MDCH plans for 2014 include: Children's Hospital of Michigan Metabolic Clinic newsletter article, ~5 regional newborn screening trainings for birthing hospital staff, social media, completing phone contact with all MI prenatal care providers, and packet for college health clinics.
- IRB and SAB:** 4 formal requests have been made for blood spots in 2014. 3 have been approved and 1 is pending review and approval (Please see attached research update.). Three additional formal inquiries by researchers have been made. Carrie is working on updating the on-line Research Report with lay and research abstracts.
- Satisfaction Survey:** Distributed as part of MDCH program scorecards. 6 respondents. Overall satisfaction expressed with group. Request for more information on research to better answer community questions. Research update is a standing agenda item but a brief written summary of new approved research will be distributed to board members prior to each meeting. A portion of September's agenda will be devoted to invited researcher presentations. The board is asked to please contact Carrie within the next few weeks with studies of interest after reading the research report available on-line.
- Consent Statistics:** During the first quarter of 2014, 81.3% of consent forms were returned completed. Of the population undergoing newborn screening, 64% of parents are consenting to participation in the BioTrust, 17.4% are actively declining and 18.7% are counted as passive declines after receiving no documented consent decision.

4. 2015-16 Membership

- Current 2013/14 roster discussed.

- i. All organizations will be invited to renew except National Alliance on Mental Illness due to their inability to participate in board meetings and voting.
 - ii. Members-at-large: Current individuals welcome to re-apply for 2015/16 seats, and applications will be distributed through the same process as in 2013. R. Beene-Harris, Tina Reynolds and Denise Chrysler agreed to sit on review committee and will meet in August to review applications and bring recommendations to the CVAB at the September meeting for voting.
- California is now the second state in the nation to have a similar group, called the California Biobank Community Values Panel, devoted to discussing blood spot storage and use. Their roster was reviewed and parallel MI organizations discussed.
 - K. Calhoun will facilitate conversations with ACCESS, American Indian Health and Family Services of Southeastern Michigan and Carrie will follow-up to determine interest. T. Jackson will facilitate conversation with Carrie and MI Family Voices to also determine interest in board and awareness activities for their families. She will also reach out to the MI Association for Local Public Health and continue conversations with MI Public Health Association's student section. Carrie will also reach out to March of Dimes to determine if any staff/volunteers have opened up for re-joining the board.
 - Carrie will follow-up with the State NBS Laboratory to determine if there is a question that can be added to the Directive to Destroy form to determine the reasons people are requesting destruction of their own or their child's blood spots.

5. Public Comments

- A. Brovont informed board that Dr. A. Mongoven is holding a focus group with ACCESS in June and will distribute the next draft of her PowerPoint presentation for comments.
- Mrs. E. Hill De Loney encouraged the board to invite researchers to the September meeting to discuss their on-going work and any available results. Carrie will send Mrs. De Loney the current research summary table so she can provide feedback including feedback from CBOP on any particular research projects of interest.

6. Upcoming CVAB Meeting Agendas

- September 8, 2014