



BioTrust Community Values Advisory Board Minutes  
 Monday, September 9, 2013  
 Detroit, MI

**CVAB Members Present**

*Voting Members*

<input type="checkbox"/> Linda Burghardt	<input checked="" type="checkbox"/> Tedra Jackson	<input checked="" type="checkbox"/> **Tressa Orthmeyer	<b>CVAB Designees</b>
<input checked="" type="checkbox"/> Karen Calhoun	<input checked="" type="checkbox"/> Joyce Kornbluh	<input checked="" type="checkbox"/> Stephen Rapundalo	<input checked="" type="checkbox"/> *John Roy Castillo
<input checked="" type="checkbox"/> Denise Chrysler	<input checked="" type="checkbox"/> Neil MacVicar	<input checked="" type="checkbox"/> Tina Reynolds	<input type="checkbox"/> **Peggy Rush
<input checked="" type="checkbox"/> Susan Dendrinis	<input type="checkbox"/> *Mary Lou Mason	<input type="checkbox"/> Thomas Rich	
<input checked="" type="checkbox"/> Rosalyn Beene Harris	<input checked="" type="checkbox"/> Ella Greene-Moton	<input type="checkbox"/> Rita Walters	

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

*MDCH Staff:* Janice Bach, Carrie Langbo

**1. Welcome and Introductions... *Tedra Jackson***

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

**2. Public Comments**

- None at this time. Public comments were later made and are summarized below.

**3. Review of 5.6.13 Minutes**

- T. Jackson entertained a motion to approve the 5/6/13 minutes with minor revisions to include correct spelling of Ms. E. Greene-Moton’s name and attendance for Ms. D. Chrysler. T. Orthmeyer seconded motion. All members approved minutes.

**4. 2013 CVAB Education and/or Engagement**

- Michigan State University, Ann Mongoven: Please refer to attached PowerPoint presentation. Presentation developed with intent for on-line or in-person use for individual/group presentation and includes polling application. Detailed comments requested in October with December completion goal. Piloted with 3 focus groups with one additional planned to reach minority groups. Initial comments and feedback provided to Dr. Mongoven. Slides distributed electronically for additional feedback following today’s meeting.
- Universal Kidney Foundation, Yvonne Lewis: Please refer to attached PowerPoint presentation. Ms. Lewis previously served as a member on the BioTrust CVAB and has continued making BioTrust outreach a priority. Slides summarize her work done to reach over 3,000 people and distribute ~750 pieces of written material. Discussion ensued about: (1) reaching African American or other minority populations that feel research may be “used against them”, (2) engaging and educating young adults, (3) developing conversation pieces for all ages, (4) prenatal education and (5) education of those outside of audiences of reproductive age planning for a family.
- CVAB Member Updates: (1) MAGC: member updates at annual education conference with request that MDCH NBS/BioTrust fact card be distributed after all counseling sessions. (2) MMHC: BioTrust information will continue to be looped into outreach activities. (3) MichBio: MichBio will feature an article in 2014 and facilitate inclusion of MDCH/BioTrust during October event at the State Capitol. (4) Member at Large, Karen Calhoun: Exploring BioTrust breakout session for Annual Community Engagement Program Spring Symposium. (5) Member at Large, Ella Greene-Moton: On-going agenda item for CBOP, will explore incorporating information in the MABSW conference in November and determine how to work with MI Chapter of APHA to disperse information. (6) MI Env. Council: helps share and re-tweet MDCH social media posts, includes information in

conversations with researchers and seeks potential members of interest, i.e. tribal group, for the CVAB. (7) Network for Public Health Law: continue work with NBSTRN and educating public health law classes. (8) ACLU: compose another article for MI quarterly newsletter. (9) MCMCH: reach nurses at chapter and state level through conferences and presentations. (10) DD Council: continue to distribute resources at conference primarily reaching parents of children with disabilities.

- **MDCH Update:** Governor's proclamation issued identifying September 2013 as Newborn Screening Awareness month. Michigan selected by Association of Public Health Laboratories to host their traveling exhibit from September 9-20<sup>th</sup> recognizing the nation's 50<sup>th</sup> anniversary of newborn screening. The exhibit along with Michigan's BioTrust display and other program pieces will be touring Michigan with events in Ann Arbor, Detroit and Grand Rapids. The recognition activities will culminate with the exhibit on display in the State Capitol Building for one week and a press conference with invited speakers. The BioTrust is featured during all activities. Work is on-going to revise the MDCH BioTrust website, distribute second edition of the Community Lay Report summarizing 2013 approved research protocols, and developing a speaker packet for those CVAB and community members who want to disseminate information about the BioTrust.
- **Action Item:** CVAB members confirmed community outreach is priority for them to pursue v. simply advising MDCH on activities to be undertaken. Documentation form will be developed and distributed for members to track and report to MDCH. Updates will remain an agenda item, and members were encouraged to contact Carrie if they want additional agenda time.

## 5. MDCH Updates

- **BioTrust and IRB:** 8 Studies approved in 2013 are listed in Research Report on BioTrust website ([www.michigan.gov/biotrust](http://www.michigan.gov/biotrust)). Two more studies are approved and pending final paperwork. Several additional inquiries. 2<sup>nd</sup> edition of Community Research Lay Report will be on-line by December. MDCH Policy 11.4 has been revised to include the requirement of informed consent for specific studies using whole genome or whole exome sequencing. CVAB members were requested to review the policy distributed electronically with comments requested in 2-3 weeks.
  - i. Discussion: Should research protocols be presented to the CVAB? CVAB members sit on the MDCH IRB and BioTrust SAB and take part in the review of every proposal requesting blood spots. Intellectual property rights of the researchers must be protected, thus their proposals will not be presented in an open forum for discussion, but summaries of approved research will be presented at up-coming meetings with invitations extended to researchers for presentations on their work using blood spots.
- **Midwife Survey and Outreach:** Time expired thus information on this outreach project will be tabled until the next CVAB meeting.

## 6. Public Comments

- Public comments should be taken 15 minutes prior to the close of the meeting, not near the beginning.

## 7. Michigan Neonatal Biobank Tour

- Interested committee members, guests and staff were given the opportunity for a tour of the biobank facility.