

**Congenital and Inherited Disorders Advisory Committee**  
**Minutes**  
**October 20, 2017**  
**1:00 p.m. to 3:00 p.m.**  
**Drake Public Library Grinnell, IA and Conference Call**

**M i n u t e s**

<u>Members Present</u>	<u>Members Absent</u>	<u>Others Present</u>
Lori Murphy-Stokes	Bobbi Buckner Bentz	Kimberly Noble Piper
George Wehby	Tom Scholz	Carol Johnson
Hannah Bombei	Stewart Boulis	Emily Phillips
Stanton Berberich	Andrea Greiner	Seth Perlman
Stacy Frelund	Sandra Daack-Hirsch	Jake Michaelson
Kimberly VonAhsen	Kelly Schulte	Travis Henry
Beth Tarini	Becky Lutgen Gardner	
Amanda Devereaux		
Carol Johnson for Val Sheffield	Val Sheffield	
	Dan Rowley	
	Francis Degnin	
	Paul Romitti	
	Nate Noble	
	Carrie Bernat	
	Representative Wessel Kroeschell	
	Senator Ragan	

<b>Topics</b>	<b>Discussion/Action</b>
<b><u>Call to Order</u></b>	<ul style="list-style-type: none"> <li>▪ Tarini called the meeting to order at 1:15 pm.</li> <li>▪ Roll call attendance was taken. No quorum is present. Kim Piper is connecting remotely due to car trouble.</li> </ul>
<b><u>Approval of January 27, 2017 minutes</u></b>	Vote on minutes from January 27, 2017 – Minutes approved as written, once quorum was present.
<b><u>Introductions</u></b>	Piper introduced Amanda Devereaux as a new member. Devereaux is the parent of a child with congenital CMV, and is very familiar with the advocacy and legislative process. She is also a nurse in Des Moines. The committee members welcomed Devereaux to the group.
<b><u>IDPH Budget Reductions</u></b>	Piper provided an update on the status of the CCID program budgets for state fiscal year (SFY)17 and SFY18. All IDPH programs saw a reduction in funding for SFY17. For SFY18, the Metabolic Formula and Medical Foods state budget was eliminated completely. The IDPH Executive Team had to make some very tough decisions with a drastically reduced state appropriation, which included an unfunded mandate to develop a medical cannabidiol oil program. Other CCID programs were funded based on the reduced SFY17 levels.
<b><u>Amending research proposal Augmenting Genetic Studies of Neurodevelopment with Metabolite Data.</u></b> <i>Dr. Jacob Michaelson</i>	<p>Dr. Michaelson provided a presentation to request approval for an expansion to his current research study. (attached). Proposed amendment:</p> <ul style="list-style-type: none"> <li>• allow ICTS @ UI (Institute for Clinical and Translational Science) to act as a third party broker to link neonatal screen IDs with health records, then return to us as a de-identified linked data set <ul style="list-style-type: none"> <li>&gt;&gt; for example: State Hygienic Lab gives ICTS names/DOBs of individuals it has on record</li> <li>&gt;&gt; ICTS matches to EMR based on DOB and name</li> <li>&gt;&gt; ICTS removes identifying information and returns to us</li> </ul> </li> </ul>

	<p>a data set of de-identified EMR data linked to neonatal screen IDs</p> <ul style="list-style-type: none"> <li>• ethnicity/race data for de-identified screen results (we currently have DOB, sex, hospital, but race/ethnicity may be important for normalization purposes)</li> <li>• possibility of access to blood spots for selected anonymized individuals with a diagnosis (e.g., autism)</li> </ul> <p>Discussion was held about how to obtain the data requested for the expanded study. Race/ethnicity is not available through newborn screening program records, and while vital records documents the infant's race/ethnicity on the birth certificate, the mother's race is often what is used as a surrogate for the baby's race/ethnicity. It was determined that Dr. Michaelson and Dr. Berberich will work with Dr. Paul Romitti to explore options for data collection. A vote on approval of the amendment is deferred until logistics are figured out</p>
<p><b><u>Developmental funds request for Improvements to Cystic Fibrosis Transmembrane Conductance Regulator (CFTR) Variant Testing for the Iowa Newborn Screening Program</u></b> <i>Dr. Travis Henry</i></p>	<p>Dr. Henry presented a proposal requesting the use of developmental funds to improve Cystic Fibrosis Transmembrane Conductance Regulator (CFTR) variant testing for Cystic Fibrosis newborn screening. (attached). After discussion, motion passed to recommend approval of use of developmental funds for this quality improvement activity for newborn CF testing.</p>
<p><b><u>CCID Policy #006 NBS for premature and low birthweight babies *</u></b> <i>Carol Johnson</i></p>	<p>The policy for newborn screening for premature and low birthweight babies was presented by Carol Johnson. Differences of screening premature and low birthweight babies and "normal" newborns were reviewed, as was the need for this policy. Also noted was that this policy will not be implemented immediately, due to changes needed in the lab's information system to allow tracking and monitoring of these results. Motion to approve implementation of this policy, once the infrastructure is in place, was carried. *</p>
<p><b><u>New Conditions Deliberative Community Engagement Project update</u></b> <i>Piper</i></p>	<p>Piper gave an update on the Iowa Deliberative Community Engagement for Newborn Screening project (see attached project summary). The project is awaiting IRB approval, then it will begin recruiting participants for the community engagement event. Recruitment flyers will be presented to CIDAC members to share.</p>
<p><b><u>Adjournment</u></b></p>	<p>Meeting adjourned at 3:11 pm.</p>

\*After the meeting, it was determined that the version of policy #006 presented at the meeting was not the most recent version. The latest version will be presented to the CIDAC for voting again once an internal review is complete.