

**Congenital and Inherited Disorders Advisory Committee**  
**Minutes**  
**January 27, 2017**  
**12:00 p.m. to 2:00 p.m.**  
**Conference Call and Webinar**

**M i n u t e s**

<u>Members Present</u>	<u>Members Absent</u>	<u>Others Present</u>
Val Sheffield	Lori Murphy-Stokes	Kimberly Noble Piper
Bobbi Buckner Bentz	Tom Scholz	Carol Johnson
Hannah Bombei	George Wehby	Emily Phillips
Stanton Berberich	Andrea Greiner	Melody Hobert-Mellecker
Dan Rowley	Sandra Daack-Hirsch	Jon Bernat
Kimberly VonAhsen	Beth Tarini	Lisa Neff-Letts
Becky Lutgen Gardner	Stacy Frelund	Jenny Marcy
Stewart Boulis	Mary Larson	Myrl Holida
Kelly Schulte		Joyal Meyer
Francis Degnin		Christina Trout
Paul Romitti		Seth Perlman
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>▪ Buckner-Bentz called the meeting to order at 12:07pm.</li> <li>▪ Roll call attendance was taken. A quorum is present.</li> </ul>
<b><u>Approval of July 22, 2016 minutes</u></b>	Vote on minutes from July 22, 2016 – Minute approved as written.
<b><u>Election of Officers – Vice Chair/Chair Elect</u></b>	Nomination were solicited for the position of Vice Chair/Chair Elect of CIDAC. Berberich moved to nominate and elect Beth Tarini for the position of CIDAC Vice Chair/Chair Elect. Buckner-Bentz seconded the motion. Discussion: Tarini confirmed via email message to Berberich that she would be happy to take the position if elected. Roll call vote – Tarini elected as the new Vice Chair/Chair Elect of CIDAC.
<b><u>Iowa Administrative Rules amendments 641 IAC 4</u></b>	Piper provided an update on the status of amendments to 641 IAC 4 – Center for Congenital and Inherited Disorders chapter of administrative code. The State Board of Health approved the revised rules on January 11. The rules go before the Legislative Administrative Rules Review Committee (LARRC) on February 10. The rules were published as adopted and filed on February 1, 2017 with an effective date of March 8, 2017. Proposed amendments focus on the research use of residual newborn screening specimens and the need for the researcher to obtain informed consent from the parent or guardian prior to the release of any specimens for an approved research study.
<b><u>Policies Review and Approval</u></b>	<p>Various policies were reviewed:</p> <ul style="list-style-type: none"> <li>• CCID Policy #001, #001a, #001b – Residual Newborn Screening Specimens. Piper presented this policy, which guides the process of the release of residual newborn screening specimens and process for parent/guardian request for return or destruction of specimens. #001a and #001b consist of specific guidance for return of specimens and destruction of specimens, respectively. Members reviewed the policies and recommended edits. Piper will make the edits and distribute to</li> </ul>

	<p>CIDAC members for a vote on approval.</p> <ul style="list-style-type: none"> <li>• CCID Policy #004 – Follow-up for Newborn Not Screened at Birth. This policy provides direction for follow-up on babies who did not receive their blood-spot screening at birth. Policy approved by roll call vote of members.</li> <li>• CCID Policy #007 – Newborn Screening for Babies with Unknown Identity at Birth. This policy describes the procedure for assuring Safe Haven, adopted, or other newborns whose parentage is not known receive the newborn screening. Piper will contact birthing hospitals to see how they identify those babies in the present process, to assure this policy does not conflict with the hospital’s processes.</li> <li>• CCID Policy #006 NBS for Premature and Low Birthweight Babies. This policy is currently being edited by an ad hoc work group lead by Carol Johnson. It will be presented to CIDAC when it is in its final draft.</li> </ul>
<b><u>Presentation - Advances in Neuromuscular Therapies and Treatments - Dr. Seth Perlman</u></b>	Dr. Perlman presented information about the current state of treatments and therapies for neuromuscular and related disorders.
<b><u>Next meeting date and agenda</u></b>	The next meeting will be April 28, 2017 at the Drake Community Library in Grinnell. RERC presentation
<b><u>Adjournment</u></b>	Meeting adjourned at 2:11 pm.