

**Congenital and Inherited Disorders Advisory Committee**  
**Minutes**  
**July 19, 2019**  
**12:00 p.m. to 2:00 p.m.**  
**Zoom webinar and conference call**

**M i n u t e s**

<u>Members Present</u>	<u>Members Absent</u>	<u>Others Present</u>
Adam Brown	Sandra Daack-Hirsch	Kimberly Noble Piper - IDPH
Bobbi Buckner Bentz	Tom Scholz	Carol Johnson – U of I
	Stewart Boullis	Emily McLaughlin - Baebies
Stanton Berberich	Ashley Hinson	Emily Phillips – U of I
Kimberly VonAhsen	Nate Noble	Jacque Kotlarek – U of I
Jeremy Penn	George Wehby	Jenny Marcy – U of I
Amanda Devereaux	Representative Ashley Hinson	Mike Pentella
Hannah Bombei	Andrea Greiner	
Francis Degnin	Carrie Bernat	
Shane Austerman	Lori Murphy-Stokes	
Paul Romitti	Kelly Schulte	
	Stacy Frelund	
	Dan Rowley	
	Senator Amanda Ragan	
	Representative Wessel Kroeschell	
	Anya Prince	
	Amy Calhoun	

<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 12:05 pm.</li> <li>▪ Roll call attendance was taken. There is not a quorum of members present.</li> </ul>
<b><u>Announcements</u></b>	Piper made the announcement that the director of the Iowa Department of Public Health (IDPH), Gerd Clabaugh, has accepted Governor Reynold’s request that he serve as interim director of the Iowa Department of Human Services. He will continue to serve as the director of IDPH.
<b><u>New Committee Chair</u></b>	Buckner Bentz introduced Amanda Devereaux as the new chair of this committee.
<b><u>Nomination/election of Vice Chair/Chair Elect</u></b>	Piper – With Devereaux’s move to committee chair, we need a new vice chair/chair elect. Nominations were requesting from members on the call, and none were received. Piper will add this to the agenda for the October 2019 meeting. In the meantime, please get any nominations to Piper and she will follow-up.
<b><u>SMA Pilot Update</u></b>	Piper reviewed the SMA Pilot Summary presented to the State Board of Health on 7-10-19, and conveyed the Board of Health Chair’s appreciation for the work of the Iowa Newborn Screening Program.

<p><b>Newborn Screening Fee Increase</b></p>	<p>Piper described the status of the requested NBS fee increase. After CIDAC approval of the fee increase, Piper presented the proposed budgets and justification for the fee increase to IDPH leadership. Piper met with the division director and answered questions she had at the time. The division director met with the department director and deputy director to review the budgets and requested fee increase. At that meeting, IDPH leadership decided to not take the fee increase request forward at that time, citing lack of justification to adequately support the proposed increase, and an unfavorable political climate for the approval of any fee increases.</p> <p>Piper and the NBS program leadership revised the proposed budgets and justifications, and also wrote impact statements describing the impact to programming if the fee increase was not approved. These documents were forwarded to the interim division director, Jill Lange, and then to Director Gerd Clabaugh and Deputy Director Sarah Reisetter. The INSP leadership team has a meeting with Clabaugh and Reisetter, and the IDPH legislative liaison, Amy McCoy, on Monday July 22 to discuss the budgets and proposed fee increase.</p>
<p><b>Process for consideration of future research projects</b></p>	<p>Piper states that more and more researchers are proposing use of data or specimens from CCID programs. Since CIDAC only meets quarterly, there is not enough agenda time to consider all of the proposals. For the sake of time at this meeting, Piper will be sending out further correspondence to CIDAC members about how to address this issue.</p>
<p><b>Program Spotlight Regional Genetic Consultation Service</b></p>	<p>Hannah Bombei, Coordinator of the Regional Genetics Consultation Service (RGCS), provided information about the program, clients served, and future initiatives. The PowerPoint presentation is attached to these minutes.</p>
<p><b>Adjournment</b></p>	<p>Meeting adjourned at 1:00 pm. Next meeting October 18, 2019 at the Drake Community Library in Grinnell.</p>