

Congenital and Inherited Disorders Advisory Committee
Minutes
April 19, 2019
1:00 p.m. to 3:00 p.m.
First United Methodist Church Grinnell IA
Zoom webinar ([link to recording here](#))

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
Kelly Schulte	Stewart Boulis	Kurt Anderson - Novartis
Stanton Berberich	Ashley Hinson	Travis Henry - SHL
Stacy Frelund	Nate Noble	Emily McLaughlin - Baebies
Dan Rowley	George Wehby	Kate Segert - Biogen
Jeremy Penn	Representative Ashley Hinson	Seth Perlman – U of I
Amanda Devereaux	Andrea Greiner	Anne Atkins
Kimberly VonAhsen	Carrie Bernat	John Bernat – U of I
Anya Prince	Lori Murphy-Stokes	Emily Phillips – U of I
Hannah Bombei		Jacque Kotlarek – U of I
Francis Degnin		Jenny Marcy – U of I
Amy Calhoun		Hatem El Shanti – U of I
Paul Romitti	Senator Amanda Ragan	Christina Trout – U of I
Shane Austerman	Representative Wessel Kroeschell	Krista Adams - parent

Topics	Discussion/Action
<u>Call to Order</u>	<ul style="list-style-type: none"> ▪ Buckner-Bentz called the meeting to order at 1:05 pm. ▪ Roll call attendance was taken. A quorum is present. ▪ This meeting was recorded, and the recording link is posted here under April 19, 2019 minutes: http://idph.iowa.gov/genetics/public/advisory-committee
<u>Results and Recommendations</u> <u>SMA Pre-implementation assessment</u>	<p>Piper reviewed the SMA Pre-implementation Assessment report with members. Discussion and Q and A was held. Options for next steps were presented by Piper, Calhoun, Henry, and other members of the INSP Leadership Team. A description of an implementation pilot was provided by Henry. Piper stated that she expects to convene a steering committee for the SMA pilot, whose task it will be to determine the metrics and criteria for a successful pilot, and to monitor the pilot activities.</p> <p>CIDAC Members heard a motion by Degnin to accept the recommendation to proceed with an implementation pilot for newborn screening for SMA, and to add SMA to Iowa’s newborn screening panel pending a successful pilot. Devereaux seconded the motion. Roll call vote on the motion carried, with Berberich abstaining.</p> <p>Please see the recording for discussion details, starting at the 21:27 minute mark.</p>

<p>Recommendations from the Deliberative Community Engagement Project for Adding Conditions to Iowa’s Newborn Screening Panel</p>	<p>Piper presented a summary of the Deliberative Community Engagement for Newborn Screening project, and reviewed the recommendations put forth from the DCE deliberants. CIDAC members and interested parties held discussion on the report and recommendations. It was noted that some of the recommendations are not feasible, and, in some cases, contradict other parts of the recommendations. Piper stated that the INSP Executive Team has started to review some of the recommendations and are planning for implementation of feasible recommendations, such as establishing a “consumer” advisory group (or a similar committee). Piper asked CIDAC members for endorsement of the report, not the specific recommendations. Buckner-Bentz made a motion to accept the report, with a second by Devereaux. Roll call vote = motion carried. Discussion of this agenda item begins at the 1:19:49 minute mark of the recording.</p>
<p>Research Proposal Unresolved Issues in Newborn Screening</p>	<p>Dr. Beth Tarini presented a summary of her research proposal “Unresolved Issues in Newborn Screening: Quantifying the Harms of a False Positive Result.” Researchers from this study will be contacting parents of newborns who have received a false positive newborn screening result, and parents of newborns with normal newborn screening results, from families in Iowa and Minnesota. Current INSP staff will be responsible for identifying families for the study. Parents will be consented before participating in the study. This research proposal is awaiting IRB approval (Research study is coordinated out of Children’s National Health System.) Discussion about this agenda item can be found at minute mark 1:54:57 of the recording. Motion to approve the research proposal was made by Degnin, and seconded by Penn. Roll call vote – motion passed, with Calhoun abstaining.</p>
<p>Process for consideration of future research projects</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><u>Adjournment</u></p>	<p>Meeting adjourned at 3:20 pm. Next meeting July 20, 2019 via Zoom webinar and conference call. Proposed meeting schedule for state fiscal year 2020 was provided.</p>