

## Congenital and Inherited Disorders Advisory Committee

### Minutes

April 22, 2022

12:00 p.m. to 2:00 p.m.

Zoom and conference call

### Minutes

Video recording of the meeting is available at

<u>Members Present</u>	<u>Members Absent</u>	<u>Others Present</u>
Carol Cross	Jennifer Nutt	Kimberly Noble Piper - IDPH
Jeneane Moody	Jona Conklin	Carol Johnson – U of I
Anya Prince	Andrea Greiner	Jaclyn Kotlarek – U of I
Amy Calhoun	Tom Scholz	Wade Aldous - SHL
Barbara Pappas	Nate Noble	Lauren Pierce – South Dakota
Adam Brown	Kelly Schulte	Sara Allen – Cornerstone Govt. Affairs
Stanton Berberich		Miranda McAuliffe - ALD Alliance
Hannah Bombei		Serena Banu Gumusoglu
Francis Degnin		Donna Santillan
Carrie Bernat		
Jeremy Penn	Senator Amanda Ragan	
Amanda Devereaux	Representative Beth Wessel Kroeschell	
Shane Austerman		
Paul Romitti		
Kimberly VonAhsen		
Stacy Frelund		
Dan Rowley		

<b>Topics</b>	<b>Discussion/Action</b>
<b><u>Call to Order</u></b>	<ul style="list-style-type: none"> <li>▪ Penn called the meeting to order at 12:09 pm.</li> <li>▪ Roll call attendance was taken. There is a quorum of members present.</li> </ul>
<b><u>Announcements</u></b>	Piper shared an update about the DHHS alignment.
<b><u>Nomination and Election of Vice Chair/Chair elect</u></b>	Nominations were solicited. Jeneane Moody self-nominated. Calhoun moved to elect Moody as vice chair/chair elect. Degnin 2 <sup>nd</sup> . Voice vote – motion carried. Jeneane Moody will serve as Vice Chair beginning July 1, 2022.
<b><u>Research Proposal – Prenatal Programming of Neurodevelopment</u></b>	Dr. Banu Gumusoglu presented her research proposal “Prenatal Programming of Neurodevelopment.” This study aims to “...leverage the existing metabolic data collected through the IDPH Newborn Screening Program to develop an infant blood-based biomarker for common and pervasive intellectual and neurodevelopmental disorders (IDDs) including autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD), learning disorders (LDs), developmental delay (DD), and externalizing and mood disorders (e.g. conduct disorder, anxiety, and depression). The study will retrospectively link metabolic data to medical records of children born at the University of Iowa Hospitals and Clinics (UIHC) and enrolled in the Iowa Maternal Fetal Tissue Bank (MFTB), which is directed by Dr. Donna Santillan (UIHC, Obstetrics and Gynecology).” Dr. Gumusoglu stated that patients provide informed consent to the MFTB for both

	<p>the birth person and the child.</p> <p>Discussion was held about the study, including questions about how diversity in the study population is sought, and confirmation that the researchers are not requesting residual newborn screening specimens. Some members expressed trepidation about the application of the consent to the access to the newborn's screening results - that the consent does not reach beyond the newborn screening results report in the medical record (analyte-level data are not included in the newborn screening results report in the newborn's medical record), not does it explicitly describe access to the newborn's lab data. After discussion, Penn moved to approve the research proposal as presented and as described in the research agreement application. Rowley 2<sup>nd</sup>. Roll-call vote = motion passed.</p>
<p><b>Senate File 2345/ Notice of Intended Action to Amend Admin Rules</b></p>	<p>Piper reviewed the proposed amendments to Iowa Administrative Code 641 Chapter 4 – Center for Congenital and Inherited Disorders. Changes are proposed to align with Senate File 2345, which was recently signed by the governor. Discussion was held about the changes. Some members expressed concern about the addition of language that requires a physician or other health care professional who undertakes primary pediatric care of a newborn delivered in Iowa to be available on an emergency basis to follow up on time-critical newborn screening results for newborns in the physician's or health care professional's care. Members stated this would put undue responsibility for the provider who may not have control over who covers for them when they are unavailable. Piper encouraged members and interested parties to submit comments during the public comment period for the rules.</p>
<p><b>Establishing CIDAC Subcommittee</b></p>	<p>Piper - SF2345 requires CIDAC to undertake the following activities regarding the addition of new conditions to the newborn screening panel in order to align with the federal Recommended Uniform Screening Panel (RUSP). –</p> <ol style="list-style-type: none"> <li>1. The advisory committee shall assist the center for congenital and inherited disorders and the department in designating the conditions to be included in the newborn screening and in regularly evaluating the effectiveness and appropriateness of the newborn screening.</li> <li>2. Beginning July 1, 2022, the advisory committee shall ensure that all conditions included in the federal recommended uniform screening panel as of January 1, 2022, are included in the newborn screening.</li> <li>3. Within twelve months of the addition of a new condition to the federal recommended uniform screening panel, the advisory committee shall consider and make a recommendation to the department regarding inclusion of the new condition in the newborn screening, including the current newborn screening capacity to screen for the new condition and the resources necessary to screen for the new condition going forward. If the advisory committee recommends inclusion of a new condition, the department shall include the new condition in the newborn screening within eighteen months of receipt of the recommendation.</li> <li>4. Within twelve months of the addition of a new condition to the federal recommended uniform screening panel, the advisory committee shall consider and make a recommendation to the department regarding inclusion of the new condition in the newborn screening panel, including the current newborn screening capacity to screen for the new condition and the resources necessary to</li> </ol>

	<p>screen for the new condition going forward.</p> <p>5. If the advisory committee recommends inclusion of a new condition, the department shall include the new condition in the newborn screening panel within eighteen months of receipt of the recommendation.</p> <p>To accomplish these required activities, IDPH is establishing a standing subcommittee of CIDAC that will be charged with management the newborn screening panel. This subcommittee will have 4-5 core members, with ad hoc members assigned according to their experience, expertise, and interest in the conditions. There will also be ex officio members from newborn screening program staff. We are hoping to keep the group to 8-10 members total. At least one of the subcommittee members needs to be a member of CIDAC, and will serve as the subcommittee liaison to CIDAC. These are voluntary positions – there is no reimbursement available for the subcommittee members’ effort, but travel expenses and meals will be reimbursed for members who are not state or federal employees. We will begin forming the subcommittee and planning the meetings in June, and anticipate meetings every 2 weeks for the next month or so, and regular quarterly meetings after that.</p> <p>If you are interested in being on the subcommittee, or know someone who would be (must be an Iowa resident), please let Piper know. The newborn screening program leadership will select and notify subcommittee members in early June.</p>
<b>Public Comment</b>	<p>Miranda from the ALD Alliance provided information about resources available from the Alliance to support the newborn screening program and families of children with ALD.</p>
<b><u>Adjournment</u></b>	<p>Meeting adjourned at 2:00. Next CIDAC meeting is July 22, 2022 from 12:00 pm to 2:00 pm via Zoom. (This may be rescheduled due to a conflict of Piper’s)</p>