

Congenital and Inherited Disorders Advisory Committee
Minutes
October 22, 2021
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	Kimberly VonAhsen	Georgianne Younger – U of I
Anya Prince	Andrea Greiner	Jaclyn Kotlarek – U of I
Amy Calhoun	Tom Scholz	John Bernat – U of I
Dan Rowley	Nate Noble	Maynard Friesz – Cure SMA
Adam Brown	Paul Romitti	Sara Allen – Cornerstone Govt. Affairs
Kelly Schulte	Barbara Pappas	Kelli Ryckman – U of I
Hannah Bombei	Jona Conklin	Lauren Pierce – South Dakota
Francis Degnin	Stanton Berberich	Megan Kolod
Carrie Bernat	Stacy Frelund	Paul Roesch - Baebies
Jeremy Penn	Senator Amanda Ragan	
Amanda Devereaux	Representative Beth Wessel Kroeschell	
Shane Austerman		

Topics	Discussion/Action
<u>Call to Order</u>	<ul style="list-style-type: none"> ▪ Penn called the meeting to order at 12:09 pm. ▪ Roll call attendance was taken. There is a quorum of members present.
<u>Announcements</u>	Piper shared that today is Dr. Caitlin Pedati's last day. Nalo Johnson's last day is November 4. Update on IDPH/DHS realignment. DHS/IDPH will merge into one DHHS agency. More information on the realignment work is available at https://hhsalignment.iowa.gov/
<u>Research Proposal – Electronic cigarette use during pregnancy and the impact on newborn metabolic profile and perinatal health outcomes – Dr. Kelli Ryckman</u>	Dr. Ryckman presented her proposal for approval. The CIDAC Research Proposal Review Subcommittee members recommended approval. Roll call vote = Degnin motioned approval of the proposal, Devereaux and Moody seconded. Motion passed on roll call vote. Piper explained that she has asked some members of CIDAC to serve as research proposal reviewers with the charge to review proposals, complete a review checklist, and make recommendations to CIDAC about approval of the proposals. Berberich, Romitti, Devereaux, Prince, and Degnin have all agreed to serve in this capacity.
<u>Update on newborn screening fee increase</u>	Piper stated that the NBS fee discussions are centered at the policy-maker level with IDPH leadership and the legislative liaison working with the governor's office and the legislative caucuses to advance fee increases/explore options for all IDPH programs that require fees.
<u>SMA newborn screening</u>	The State Board of Health added SMA to Iowa's newborn screening panel with a unanimous vote at their September meeting. The Iowa Newborn Screening Program has identified additional newborns with SMA. Each baby is receiving specialty care and is doing well.

<p>Pre-implementation assessment of Pompe and MPSI (LSDs)</p>	<p>Piper and Calhoun described the status of the CIDAC-commissioned pre-implementation assessment for Pompe and MPSI, which looks at the current capacity of the program to screen for Pompe and MPSI and what resources would be necessary to screen for these conditions going forward. The Newborn Screening Executive Team (NBSET) (Berberich, Calhoun, Johnson, Kappell, Piper) has decided to include other lysosomal storage disorders in this review, due to the similarities in testing methodologies, follow-up and medical management. These include Krabbe Disease, Gaucher Disease, and Fabry Disease. NBSET has just started this assessment and expects to have an update for the January CIDAC meeting, with a full report by the April meeting.</p>
<p>Newborn Screening Conditions on the Horizon</p>	<p>Piper described other conditions that are being discussed at the national/international level for addition to newborn screening panels (the Recommended Uniform Screening Panel – RUSP). These include additional MPS types; Krabbe Disease; Gaucher Disease; Fabry Disease; DMD - Duchenne Muscular Dystrophy; CMV- Cytomegalovirus; GAMT – Guanidinoacetate methyltransferase deficiency; OTC (Ornithine Transcarbamylase) Deficiency; MLD – (Metachromatic leukodystrophy); Fragile X; and conditions reviewed in the past – hyperbilirubinemia. Piper mentioned that NY State screens for HIV.</p>
<p>Public Comment</p>	<p>There were no public comments.</p>
<p><u>Adjournment</u></p>	<p>Meeting adjourned at 2:00. Next CIDAC meeting January 28, 2022 from 12:00 pm to 2:00 pm via Zoom</p>