Congenital and Inherited Disorders Advisory Committee
Minutes
April 23, 2021
12:00 p.m. to 2:00 p.m.
Zoom and conference call

Minutes
Video recording of the meeting is available at

Members Present	Members Absent	Others Present
Barbara Pappas	Jennifer Nutt	Kimberly Noble Piper - IDPH
Jona Conklin	Kimberly VonAhsen	Carol Johnson – U of I
Jeneane Moody	Andrea Greiner	Tate Kappell - SHL
Amy Calhoun	Tom Scholz	Wade Aldous - SHL
Dan Rowley	Nate Noble	Georgianne Younger – U of I
Adam Brown		Jaclyn Kotlarek – U of I
Kelly Schulte		Dee George - Novartis
Hannah Bombei		John Bernat – U of I
Stacy Frelund		Joyal Meyer – North Dakota NBS program
Stanton Berberich		Mary Schroth – Cure SMA
Francis Degnin		Maynard Friesz – Cure SMA
Paul Romitti		John Bernat – U of I
Anya Prince		Ashley Ramirez - SHL
Carrie Bernat	Senator Amanda Ragan	Emily McLaughlin - Baebies
Jeremy Penn	Representative Wessel Kroeschell	Ryan Colburn - public
Amanda Devereaux		Christopher Haberman-public
Shane Austerman		Jenna Yarborough - public
Cross		Amy Smith - public
		Sarah Turnbull - public
		Melody Hobert-Mellecker – U of I
		Jaclyn Kotlarek – U of I
		Sara Allen – Cornerstone Govt. Affairs
		Zoey De Wolf - Sanofi
		Jenny Marcy – U of I

Topics	Discussion/Action
Call to Order	▪ Frelund called the meeting to order at 12:05 pm. ▪ Roll call attendance was taken. There is a quorum of members present.
Announcements	Piper shared that the IDPH has a grant from CDC and has entered into an agreement to have the Iowa Registry for Congenital and Inherited Disorders (IRCID) conduct surveillance activities for pregnant women who have tested positive for COVID-19.
Update on Proposed Newborn Screening Fee Increase	Piper presented the latest information about the status of the newborn screening fee increase proposed in 2017. The current political climate has not been favorable to fee increases in any state

	programs (not just NBS). After the current legislative session adjourns, discussions will resume on the best way to provide sustainable fiscal support for the Iowa Newborn Screening Program (INSP). Moody – can CIDAC members receive a copy of the revised fee increase proposal that is presented to IDPH leadership? Piper – yes. Moody – Motions to convene CIDAC to draft a Letter of Support for the proposed fee increase. Degnin 2nd. Roll call vote = motion passed. Austerman – would like to consider funds to help treat patients as part of the NBS fee, similar to Georgia and Wisconsin. Piper – can Austerman provide that information to be included in the proposal? Austerman – yes.
SMA Newborn Screening Pilot update	Piper summarized the status of the pilot, which started July 1. All of the goals/targets of the performance measures and metrics developed by the SMA Pilot Steering Committee have been met. One newborn was identified with SMA and is receiving specialty care at the Neuromuscular Clinic. Joyal Meyer, Director of the North Dakota NBS Program, stated the North Dakota will add SMA to its screening panel and begin routine SMA screening on September 1. The Iowa Newborn Screening Executive Team (Berberich, Calhoun, Johnson, Kappell, and Piper) has made the decision to consider the pilot successful, and to move to routine SMA newborn screening starting September 1 also. The INSP will still need to get approval from the State Board of Health to add SMA to the screening panel, and Piper will work to get the required fee increase and amendment of the Administrative Rules approved by IDPH leadership, the Board of Health, and the Legislative Administrative Rules Review Committee. INSP applied for year 2 funding from CDC to cover the costs of SMA screening until such time the fee increase is approved and implemented. Voice vote = CIDAC approval of the proposed plan.
Subcommittee Review of Pompe and MPS1	Jenny Marcy, Chair of the Management of the Newborn Screening Panel Subcommittee, summarized the work of the Subcommittee's review of Pompe and MPS1 for consideration for addition to Iowa's newborn screening panel. The slides summarizing this work are attached. The Subcommittee reviewed these conditions for their appropriateness for addition to the newborn screening panel and provided results of a Subcommittee member vote on whether Pompe and SMA1 are appropriate for the Iowa newborn screening panel. Pompe = yes; MPS1 = yes. After some questions/answers, Devereaux made a motion to move on to the next phase of the review process and commission an implementation assessment. The INSP Executive Team will begin an assessment of the current capacity of the INSP to screen for these conditions, and what resources would be needed to build that capacity. Penn 2nd the motion. Roll call vote = motion carried. After the implementation assessment, CIDAC may vote to commission a pilot screening program for Pompe and MPS1. This process would take about a year and a half.
Public Comment	Colburn, Haberman, and Smith provided public comments related to Pompe and MPS1 newborn screening. Yarborough provided comments in the meeting chat, which Piper read aloud. Colburn, Haberman, and Yarborough also provided written comments, which were shared with CIDAC members (attached to these minutes).
OTTER Project Update	Johnson - The INSP received cooperative agreement funding from the Association of public Health Laboratories (APHL) to use a quality improvement process to provide newborn screening education during the prenatal period. We call it the Opportunities for Training Through Educational Resources (OTTER) project. We have partnered with four clinics that provide prenatal care to pregnant women. The clinic staff will provide their pregnant clients with business cards that have

	information about how to connect with a new NBS education website - the newborn screening Wiki. This Wiki has information about all three newborn screening programs (blood spot, hearing and critical congenital heart disease), and allows the woman to submit questions to the INSP staff. It is in English only for the time being, with a Spanish version coming soon.
Continuity of Operations Plan (COOP) for Newborn Screening	Johnson - The Iowa Newborn Screening Executive Team received a technical assistance and funding grant from the Association of Public Health Laboratories (APHL) to enhance our newborn screening continuity of operations plan. Our current COOP is lab focused and does not provide guidance for the entire newborn screening system, including follow-up, referrals, family notifications, etc. Nor does the current COOP address national or international emergencies that may impact the program This work will be done by a core team of newborn screening program staff, with solicitation of input and expertise from stakeholders.
Adjournment	Meeting adjourned at 2:00. Next CIDAC meeting July 23, 2021 from 12:00 pm to 2:00 pm via Zoom