Congenital and Inherited Disorders Advisory Committee
Minutes
January 22, 2021
12:00 p.m. to 2:00 p.m.
Webex and conference call

Minutes
Video recording of the meeting is available at

https://idph.webex.com/recordingservice/sites/idph/recording/7d07695ba7ab4c3bb1303cdeb20b0f8d/playback

Members Present	Members Absent	Others Present
Adam Brown	Jennifer Nutt	Kimberly Noble Piper - IDPH
Barbara Pappas	Amanda Devereaux	Georgianne Younger – U of I
Carrie Bernat	Dan Rowley	Mike Pentella - SHL
Stanton Berberich	Tom Scholz	Carol Cross
Kimberly VonAhsen	Nate Noble	David Adelman – Cornerstone Govt. Affairs
Jeremy Penn	Francis Degnin	Jaclyn Kotlarek – U of I
Stacy Frelund	Jona Conklin	Dee George
Hannah Bombei		John Bernat – U of I
Kelly Schulte		Tate Kappell - SHL
Shane Austerman		Mary Schroth – Cure SMA
Paul Romitti		Kurt Anderson – Novartis Govt. Affairs
Andrea Greiner		Joyal Meyer – North Dakota NBS program
Amy Calhoun		Ashley Ramirez - SHL
Anya Prince	Senator Amanda Ragan	Elizabeth McDonald Blume - SHL
Jeneane Moody	Representative Wessel Kroeschell	Abigail Parras
		Jaclyn Kotlarek – U of I
		David Adelman
		Sara Allen
		Paul Roesch

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	Shane Austerman shared that HF50 "An Act relating to third-party payment of insurance benefits for medically necessary food, and vitamins and individual amino acids, for certain covered conditions, and including applicability provisions" has been introduced in the Iowa House and assigned to the Commerce Committee. Contact Austerman if you are interested in learning more.
SMA Newborn Screening Pilot update	Piper summarized the status of the pilot, which started July 1. Elizabeth McDonald Blume provided an update from the SHL – 26,427 babies have been screened (included ND babies)since the pilot began. The assay is performing as expected. No cases have been identified as yet (one indeterminate result resulted in a normal finding after additional testing). Dr. Mary Schroth with Cure SMA stated that they are seeing incidence rates of 1:5000 to 1:25,000, with an average of

	1:14,000. As more states screen for SMA, the incidence will become clearer.
Subcommittee Review of Pompe and MPS1	On behalf of Jenny Marcy, Piper summarized the work of the CIDAC Subcommittee for Management of the Iowa Newborn Screening Panel's. review of Pompe and MPS1 for consideration for addition to Iowa's newborn screening panel. The slide summarizing this work to date is attached. The subcommittee will review these conditions for their appropriateness for addition to the newborn screening panel and is anticipated to provide an update/recommendation at the April CIDAC meeting. The next step would be for CIDAC to request an implementation assessment (looking at the feasibility of conducting the screening with existing resources and determining what resources would be needed), then CIDAC would potentially commission a pilot screening program for Pompe and MPS1. This process would take about a year and a half.
Newborn Screening Family Follow-up Calls	Georgianne Younger, licensed genetic counselor with the newborn screening program, provided a presentation on the family contact program. Younger's presentation is attached to these minutes.
Continuity of Operations Plan (COOP) for Newborn Screening	The Iowa Newborn Screening Executive Team applied for 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.
Open Discussion	Meyer asks if the newborn screening pilot does not find a case prior to the anticipated end date of June 30, will the program still "go live" with SMA screening July 1, or will the pilot continue until a case is found and followed-up? Berberich states since the intent of the pilot is to not only make sure the test performs as expected, but that the entire NBS process functions as it should. In order to do this, we would need to continue the pilot until we had at least one case from each state.
Adjournment	Meeting adjourned at 1:05. Next CIDAC meeting April 23, 2021 from 12:00 pm to 2:00 pm via Webex.