

**Congenital and Inherited Disorders Advisory Committee**

**Minutes**

**July 24, 2020**

**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/recording-service/sites/idph/recording/playback/0508a2a9b9c349c881e89b4609c883ec>

<u>Members Present</u>	<u>Members Absent</u>	<u>Others Present</u>
Adam Brown	Jennifer Nutt	Kimberly Noble Piper - IDPH
Jona Conklin	Barbara Pappas	Carol Johnson – U of I
Carrie Bernat	Dan Rowley	Mike Pentella - SHL
Stanton Berberich	Tom Scholz	Jenny Marcy – U of I
Kimberly VonAhsen	Nate Noble	David Adelman – Cornerstone Govt. Affairs
Jeremy Penn	Representative Ashley Hinson	Jaclyn Kotlarek – U of I
Amanda Devereaux		Wade Aldous - SHL
Hannah Bombei		John Bernat – U of I
Francis Degnin		Christina Trout – U of I
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
Stacy Frelund	Senator Amanda Ragan	
Jeneane Moody	Representative Wessel Kroeschell	
Anya Prince		
Kelly Schulte		

<b>Topics</b>	<b>Discussion/Action</b>
<b><u>Call to Order</u></b>	<ul style="list-style-type: none"> <li>▪ Devereaux called the meeting to order at 1:5 pm.</li> <li>▪ Roll call attendance was taken. There is a quorum of members present.</li> </ul>
<b><u>Announcements</u></b>	<ul style="list-style-type: none"> <li>▪ Piper announced that at the last CIDAC meeting (October 2019) members were to vote their approval for the use of developmental funds to support the SMA newborn screening pilot. Members voted online with unanimous approval.</li> <li>▪ Carol Johnson stated that a new genetic counselor (GC) has been hired. Georgianne Younger will provide backup support to the other NBS GCs, will provide telehealth counseling for newborns with a positive NBS (usually hemoglobinopathies, CF, SCID and CAH), and will contact families of newborns with a positive NBS 24 hours after the PCP has notified the parents of the results.</li> <li>▪ Devereaux asked about the status of the request for an increase in the newborn screening fee. Piper said that Director Clabaugh had requested revised budgets for his consideration, which the SHL has provided, but Clabaugh is now retiring as of July 31, so this</li> </ul>

	will fall to the interim director, Kelly Garcia. The Division Director, Nalo Johnson, understands the importance of moving this request forward, and will work with Director Garcia.
<b>SMA Pilot Update</b>	Berberich summarized the status of the pilot, which started July 1. A few very minor bumps on the first day that were handled without any problems. Travis Henry, scientist at SHL, had stated that he wished all new condition rollouts went this smoothly. Dr. Mary Schroth with Cure SMA congratulated the INSP on a successful pilot kick-off.
<b>Annual Review of the Iowa Newborn Screening Panel</b>	Marcy provided a presentation summarizing the work of the CIDAC Subcommittee for Management of the Iowa Newborn Screening Panel. A couple of points from the presentation: no medical consultant assigned to provide expertise to the CCHD newborn screening program; the CCID Policy #3 describes the process for adding a condition, but not for removing a condition (Piper says that the State Board must approve the removal of conditions from the panel); next conditions to review would be those on the Recommended Universal Newborn Screening Panel (RUSP) – Pompe, MPS1, and X-ALD – not sure if these should be reviewed separately or together (Dr. John Bernat, Medical consultant, recommended that Pompe and MPS1, both lysosomal storage disorders, be reviewed together as they use the same testing assay). Moody asked if health equity is considered when reviewing a condition for addition to the panel – Marcy stated that equitable access to services and treatments is included in the review. Calhoun moved to convene the CIDAC Management of the Iowa Newborn Screening Panel to review Pompe and MPS1 for possible addition to the NBS panel. Penn seconded the motion. No further discussion. Roll call vote of members – motion passed.
<b>Research Proposal: Epigenetics and the social environment in autism: A cross-sectional study</b>	Dr. Strathearn presented his proposal “Epigenetics and the social environment in autism: A cross-sectional study.” CIDAC members clarified that Dr. Strathearn is requesting residual newborn screening blood spots after obtaining parent consent through the Smartphone app. Also clarified that he is asking for the blood spots only, not the newborn screening results. Penn asks, "What if you find other conditions through your testing the residual DBS that were not intended?" Strathearn – “We will not be looking for any other conditions, and if there are incidental findings they will not be shared with parents.” Strathearn states IRB approval, including approval of the consent form, is pending. Moody makes a motion to approve Strathearn’s proposal pending IRB approval. Romitti seconded the motion. No further discussion. Motion approved by roll call vote of members.
<b>Meeting schedule for FY 2021</b>	The CIDAC meeting schedule was reviewed with members, with Piper noting that the meetings have moved from the third Friday of the month to the fourth Friday of the month to avoid conflict with the Iowa Medicaid clinical services meeting. Members approved the schedule.
<b>Adjournment</b>	Meeting adjourned at 1:45. Next CIDAC meeting October 23, 2020 from 12:00 pm to 2:00 pm via Webex.