

Congenital and Inherited Disorders Advisory Committee
Minutes
October 18, 2019
1:00 p.m. to 3:00 p.m.
Zoom webinar and conference call

Minutes
Video recording of the meeting is available at
<https://youtu.be/3mR8Me7ohsM>

<u>Members Present</u>	<u>Members Absent</u>	<u>Others Present</u>
Adam Brown	Bobbi Buckner Bentz	Kimberly Noble Piper - IDPH
Tom Scholz	Carrie Bernat	Carol Johnson - U of I
Lori Murphy-Stokes	Stewart Boulis	Travis Henry - SHL
Stanton Berberich	Ashley Hinson	Jenny Marcy - U of I
Kimberly VonAhsen	Nate Noble	Kendra Schaa - U of I
Jeremy Penn	Kelly Schulte	Jenny Marcy - U of I
Amanda Devereaux	Representative Ashley Hinson	Wade Aldous - SHL
Hannah Bombei	Anya Prince	John Bernat - U of I
Francis Degrin		Michelle Sexton - SHL
Shane Austerman		
Paul Romitti		
Andrea Greiner		
Amy Calhoun		
Dan Rowley	Senator Amanda Ragan	
Stacy Frelund	Representative Wessel Kroeschell	

Topics	Discussion/Action
Call to Order	<ul style="list-style-type: none"> ▪ Devereaux called the meeting to order at 1:10 pm. ▪ Roll call attendance was taken. There is a quorum of members present.
SMA Pilot Update	Piper reviewed the SMA implementation pilot timeline and project plan, and summarized the status of the pilot. Travis Henry and Carol Johnson reviewed the lab and follow-up portions of the project plan.
Newborn Screening Fee Increase	The INSP leadership team met with IDPH Director Gerd Clabaugh and Deputy Director Sarah Reisetter, and the IDPH legislative liaison, Amy McCoy, on Monday July 22 to discuss the budgets and proposed fee increase. Justification for the proposed fee increase was outlined, as well as ramifications to Iowa newborns and their families if the fee increase is denied. IDPH leadership has had discussions with the Governor's office about proposed fee increases, and the Governor is not willing to promote the requests unless it is a public health emergency. The political climate is such that any fee increase is seen as a "tax increase." IDPH leadership will continue to promote the fee increase.

Legislation and Advocacy	<p>Piper provides an overview of a presentation prepared by Amy McCoy, IDPH legislative liaison and policy advisor that includes a description of the difference between lobbying and advocacy. As an advisory body to the IDPH, CIDAC members are not allowed to lobby as a representative of CIDAC. CIDAC members and as a committee can advocate (support) and educate policy makers about an issue. Amy recommends CIDAC draft a letter of support for the newborn screening program's requested fee increase and for the existing process for review of new conditions to the newborn screening panel to continue without legislative mandates. This letter would be addressed to the Governor, Speaker of the House, President of the Senate, and chairs of the health and human resources appropriations subcommittees. It should be presented prior to the start of the legislative session in January.</p>
Research Proposal: Assessment of Social Environment: A Pilot Study using Smart Phone Technology	<p>Dr. Strathearn presented his proposal "Assessment of Societal Environment: A Pilot Study Using Smart Phone Technology." CIDAC members clarified that Dr. Strathearn is asking for approval for Phase 1 of the study only; not for Phase 2 (which does not have IRB approval). Strathearn will return in January to present Phase 2 after receiving IRB approval. Degrin moved to approve Phase 1 of the research proposal, with a second by Calhoun. Motion passed by role call vote.</p>
Program Spotlight Iowa Maternal Prenatal Screening Program	<p>Kendra Schaa, Certified Genetic Counselor with the Iowa Maternal Prenatal Screening Program follow-up services at the University of Iowa, provided information about the program, clients served, and future initiatives.</p>
Adjournment	<p>Meeting adjourned at 3:00. Next CIDAC meeting January 17, 2020 12:00 – 2:00 Zoom Webinar and conf. call</p>