

Congenital and Inherited Disorders Advisory Committee
Minutes
October 19, 2018
1:00 p.m. to 3:00 p.m.
Wells Fargo Bank Building/Grinnell United Methodist Church, Grinnell
Web cast

M i n u t e s

<u>Members Present</u>	<u>Members Absent</u>	<u>Others Present</u>
Sandra Daack-Hirsch	Paul Romitti	Kimberly Noble Piper - IDPH
Bobbi Buckner Bentz	Tom Scholz	Carol Johnson - U of I
Kelly Schulte	Stewart Boulis	Mike Pentella - SHL
Stanton Berberich	Ashley Hinson	Travis Henry - SHL
Stacy Frelund	Nate Noble	Sarah Dricken - SHL
Dan Rowley	George Wehby	
		Kate Segert - Biogen
Lori Murphy-Stokes	Val Sheffield	Dan Wolf - Biogen
Amanda Devereaux	Andrea Greiner	Seth Perlman - U of I
Kimberly VonAhsen	Carrie Bernat	Ashley Comer - SHL
Kori Ensley		Carolyn Jones - Biogen
Hannah Bombei		Anne Atkins
Francis Degnin		B Richter
Amy Calhoun for Val Sheffield		K Adams
		John Bernat - U of I
	Representative Wessel Kroeschell	Emily Phillips - U of I
Senator Ragan sent message ahead of mtg		Jacque Kotlarek - U of I
		Jenny Marcy - U of I
		Megan & Maddie Ramirez
		Sarah & Stella Turnbull

Topics	Discussion/Action
<u>Call to Order</u>	<ul style="list-style-type: none"> ▪ Buckner-Bentz called the meeting to order at 1:05 pm. ▪ Roll call attendance was taken. A quorum is present. ▪ This meeting was recorded, and the recording link is posted here under October 19, 2018 minutes: http://idph.iowa.gov/genetics/public/advisory-committee
<u>Change of venue</u>	<i>Due to accessibility restrictions (Wells Fargo has no elevator or wi-fi, and meeting rooms and restrooms were on second floor), the location for the meeting is moved to the Grinnell United Methodist Church. Everyone present moves to the new venue which is accessible to those in wheelchairs.</i>
<u>SMA Deliberation and vote</u>	<p>Buckner-Bentz reminds attendees of the CIDAC SMA webinar September 21, 2018, where information about the course of the disease, treatments available, efficacy of treatments, cost of treatments, and public comments were heard.</p> <p>Piper discussed newborn screening as a public health program, and the responsibility of the Department and the Iowa Newborn Screening Program to the Iowa newborn population and their families. As a mandated screening program, the INSP needs to justify the public benefit of mandatory screening and the “promise” of expected benefits that outweigh potential harms. The State needs to be relatively certain that is not mandating a program detrimental to the wellbeing</p>

	<p>of the newborn population. INSP is not a case-finding or diagnostic program, nor is its mission to support clinical care. INSP provides the risk-based information to clinicians and health care providers in order for them to develop a plan of care for the newborn.</p> <p>Additional comments and clarification of the latest FDA summary for Nusinersen were heard.</p> <p>CIDAC Members heard a motion by Daack-Hirsch to accept the SMA information presented, and to commission a pre-implementation assessment from the INSP leadership team. Bombei seconded the motion. Discussion – Degrin asked if the assurance of good outcomes and that the benefits offset the costs of screening would be assessed through this process. Berberich stated that would be part of the assessment. (For components of the pre-implementation assessment see CCID policy #003, attached.).</p> <p>Vote on the motion carried.</p> <p>Please see the recording for discussion details.</p>
<u>Election of new officer: Vice Chair/Chair-elect</u>	<p>With the departure of Dr. Beth Tarini, the Vice chair/Chair elect position is vacant. Buckner-Bentz called for nominations for the position. Amanda Devereaux self-nominated. Daack-Hirsch moved to approve Devereaux as new Vice-chair/Chair elect, with a second by Buckner-Bentz. Motion carried. Stacy Frelund indicated her interest in serving in the Vice-chair/chair elect position for the next term.</p>
Proposal: New Conditions Under Consideration for Iowa’s Newborn Screening Panel	<p>Dr. Amy Calhoun and Emily Phillips presented their newborn screening quality improvement proposal to use residual newborn screening specimens and data from clinically identified children (consented) to develop screening methodologies for new conditions being considered for addition to Iowa’s newborn screening panel. Since this is a newborn screening program quality improvement program, it is not considered “research.”</p> <p>Degrin moved to approve the proposal, and Bombei seconded. Members voted to approve proposal.</p>
Request for Approval for renewal of research study	<p>Dr. Jacob Michaelson has requested an extension of his previously approved research study “Genetics of Neurodevelopmental Conditions” The IDPH Research and Ethics Review Committee requires research studies to apply for renewals every two years. CIDAC members approved the continuation of the study for another two years on a voice vote. The Committee requested that Dr. Michaelson present his findings at a CIDAC meeting in the near future. Piper will invite him to a future meeting.</p>
Report from CMV Conference	<p>Amanda Devereaux attended the National CMV Public Health and Policy Conference in September. Sessions included advocacy for policy development, raising awareness of CMV, treatment for symptomatic children, costs of symptomatic CMV infection, targeted screening versus universal screening for congenital CMV (cCMV), grassroots advocacy, testing assays for CMV, and the evaluation of cCMV-related hearing loss.</p> <p>There was consensus among leading experts that universal newborn CMV screening should be adopted. Many hospital systems around the country are already doing this, and Ontario will be adopting universal screening soon. Several states have CMV laws passed, and more have legislation submitted. The FDA recently approved saliva testing for CMV in newborns. The National CMV Foundation, along with leading experts will be submitting a proposal to the RUSP committee.</p>
<u>Adjournment</u>	<p>Meeting adjourned at 3:20 pm. Next meeting January 18, 2019. Zoom webinar and conference call.</p>

