Congenital and Inherited Disorders Advisory Committee
Minutes
January 28, 2022
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
Carol Cross	Kelly Schulte	Kimberly Noble Piper - IDPH
Jeneane Moody	Kimberly VonAhsen	Travis Henry - SHL
Stacy Frelund	Andrea Greiner	Christina Trout - U of I
Amy Calhoun	Tom Scholz	John Bernat – U of I
Jennifer Nutt	Nate Noble	Carol Johnson – U of I
Barbara Pappas	Hannah Bombei	Sara Allen – Cornerstone Govt. Affairs
Paul Romitti	Dan Rowley	Emily Phillips – U of I
Stanton Berberich	Jona Conklin	Melody Hobert-Mellecker U of I
Francis Degnin	Shane Austerman	Mike Pentella - SHL
Carrie Bernat	Adam Brown	Kristin Conway – U of I
Jeremy Penn		Joyal Meyer – North Dakota
Amanda Devereaux	Representative Beth Wessel Kroeschell	
Anya Prince	Senator Amanda Ragan	

Topics	Discussion/Action
Call to Order	▪ Frelund called the meeting to order at 12:09 pm. ▪ Roll call attendance was taken. There is a quorum of members present.
Announcements	No announcements
Iowa Registry for Congenital and Inherited Disorders	Dr. Paul Romitti presented information about the IRCID surveillance program and its operations and aims. Other activities of the IRCID will be presented at the April CIDAC meeting.
Proposal – MDSTARnet surveillance	Romitti described the MDSTARnet project for surveillance of newborns and infants with muscular dystrophy disorders. A roll call vote of CIDAC members results in affirmation of the continuation of the IRCID MDSTARnet surveillance program.
Research Proposal – Pesticide exposure among Iowa Agricultural Health Study participants and measures of thyroid function in their offspring (AHS-ITF)	Romitti submitted a research proposal to use newborn screening data to evaluate the impact on pesticide exposure of parents on their newborns' thyroid function. A motion to approve the research proposal was made by Penn and seconded by Calhoun. Motion passed on a roll call vote.
Request for Developmental Funds for outstanding SMA	Dr. Travis Henry introduced a proposal to use Developmental Funds to cover the outstanding balance of expenses to establish the testing methodology for the SMA Newborn Screening Implementation Pilot. Motion to approve use of developmental funds to cover the

pilot expenses	outstanding balance of the SMA Newborn screening Implementation was made by Moody with a second by Frelund. Motion passes on a roll call vote.
RUSP Alignment Legislation	Piper described potential legislation regarding INSP newborn screening panel alignment with US DHHS's Recommended Uniform Screening Panel (RUSP). Piper noted that the implementation assessment for the addition of Pompe, MPS1, Krabbe, Fabry, Gaucher, MPSII, MPSVI, and MPSVII will continue, but in the larger framework of the assessment for the Iowa Newborn Screening Program's capacity to screen for current and future RUSP conditions.
NewSTEPS Data Repository	Ramirez's presentation about the NewSTEPS Data Repository is deferred until the next meeting due to illness.
Public Comment	There were no Public Comments.
Adjournment	Meeting adjourned at 1:52pm. Next CIDAC meeting April 22, 2022 from 12:00 pm to 2:00 pm via Zoom