

Congenital and Inherited Disorders Advisory Committee
Minutes
October 23, 2015
1:00 p.m. to 3:00 p.m.
Drake Community Library
Grinnell, IA

M i n u t e s

<u>Members Present</u>	<u>Members Absent</u>	<u>Others Present</u>
Sandra Daack-Hirsch	George Wehby	Kimberly Noble Piper
Bobbi Buckner Bentz	Sarah Dricken	Carol Johnson
Christina Trout	Lori Murphy-Stokes	Elisa Seeger, Aidan Jack Seeger Foundation
Stanton Berberich	Kate Small	Dr. Alex Iannone
Francis Degnin	Andrea Greiner	Dr. Tim Starner
Paul Romitti	Shannon Sullivan	
Kelly Schulte	Kari Atkinson	
Stewart Boulis	Michelle Gogerty	
Dan Rowley	Tom Scholz	
Val Sheffield	Sarah Grotha	
Stacy Frelund		
	Representative Wessel Kroeschell	
	Senator Ragan	

Topics	Discussion/Action
<u>Call to Order</u>	<ul style="list-style-type: none"> ▪ Daack-Hirsch called the meeting to order at 1:05 pm. ▪ Roll call attendance was taken – we do not have a quorum of voting members. ▪ Quorum present at 1:15 pm
<u>Approval of April 24, 2015 and July 24, 2015 minutes</u>	Vote on minutes from April 24, 2015 and July 24, 2015 - approved.
<u>Election of Officers – Vice Chair/Chair elect</u>	Bobbi Buckner-Bentz offered to serve as Vice Chair/Chair Elect. Buckner-Bentz nominated for the position of Vice Chair/Chair Elect by Sheffield. Seconded by Romitti. Vote = motion carried. Bobbi Buckner-Bentz is elected as CIDAC Vice Chair/Chair Elect. Term starting immediately.
<u>INSIS Update</u>	Carol Johnson – The Iowa Newborn Screening Information System, the new data system for the blood spot, hearing and critical congenital heart disease screening programs, is continuing its user-acceptance testing. Newborn screening lab messages will be available for testing of the newborn screening module in December.
<u>Informed Consent Subcommittee Update</u>	<ul style="list-style-type: none"> ▪ Dr. Daack-Hirsch –The Informed Consent Subcommittee has drafted a parent informational brochure and a consent form based on The Michigan Bio-trust’s documents. IDPH has opened up the administrative rules 641 IAC 4 to amend the date for having policies & procedures for obtaining informed consent developed from January 2016 until July 1, 2017. This would help us pilot consenting procedures, examine federal regulations, and perhaps find funding to support. Funding will be required to provide for

	implementation and sustainability of the informed consent process.
<u>Newborn Screening Panel Management Subcommittee report</u>	<ul style="list-style-type: none"> ■ Jenny Marcy reports that the subcommittee has drafted a policy for the management of Iowa’s newborn screening panel. Piper will distribute to committee members for a vote of approval at the next meeting. The subcommittee is examining two lysosomal disorders for addition to the newborn screening panel – Pompe’ and MPS 1. Both conditions have been recommended by the Advisory Committee for Heritable Diseases in newborns and Children for the national uniform screening panel, pending the Secretary of DHHS approval. Christina Trout expresses concern that the neuromuscular program has not been involved in the discussions about Pompe’, since it is a neuromuscular condition. Trout and Dr. Katherine Mathews will be included in future meetings as the subcommittee reviews these conditions.
<u>Public Comment ALD</u>	<ul style="list-style-type: none"> ■ Ms. Elisa Seeger from the Aiden Seeger Foundation spoke to the members and guests present about Adrenoleukodystrophy (ALD). Ms. Seeger requested the committee strongly consider adding ALD to the newborn screening panel. She offered assistance to the committee as they consider this request.
<u>Research Proposal – Inflammation, the IGF system, and growth in infants with CF</u>	<ul style="list-style-type: none"> ■ Dr. Alex Iannone presented a research proposal that includes a request to use residual newborn screening specimens from newborns diagnosed with CF and Deidentified control cases. The parents of the CF children (identified) have already consented. The research seeks to examine growth factor in newborns compared to birthweight and future growth in children with CF. ■ Vote to recommend proposal as presented – motion by Romitti, Second by Daack-Hirsch. Motion carried.
<u>CoIIN Timeliness in Newborn Screening Project</u>	<ul style="list-style-type: none"> ■ Stan Berberich updated the members on the state’s timeliness in newborn screening Collaborative Improvement and Innovation Network project. Iowa has a goal of 95% of newborn screening collection forms being received by the State Hygienic Laboratory in Ankeny within 60 hours of birth. Pilot hospitals have all been receiving infographics and other requested data to help them assess their processes. An educational webinar is planned for all newborn screening providers prior to the roll-out of the infographics statewide. Hospital staff have been very engaged, and word of mouth has also served to get other hospitals besides those in the pilot online.
<u>Next meeting date and agenda</u>	<p>The next meeting will be January 23 via conference call. Piper may request to move the date to January 16 or 30, as she now has a conflict on the 23rd.</p> <p>Program reports will be provided. Vote to approve the Management of the Newborn Screening Panel policy.</p>
<u>Adjournment</u>	Meeting adjourned at 3:15 pm.