

Congenital and Inherited Disorders Advisory Committee
Minutes
October 24, 2014
1:00 p.m. to 3:00 p.m.
Drake Community Library, Grinnell, Iowa

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
Stewart Boulis	Sarah Dricken	Carol Johnson
Lori Murphy-Stokes	Andrea Greiner	Myrl Holida
Val Sheffield	Dan Rowley	Marcus Johnson-Miller
Kate Small	Shannon Sullivan	
Bobbi Buckner Bentz	Debra Waldron	
Kate Small	Cathy Evers	
Kelly Schulte*	Michelle Gogerty	
Stacy Frelund*	Kari Atkinson	
Stanton Berberich		
Francis Degnin	Representative Wessel Kroeschell	
Paul Romitti	Senator Ragan	
Sarah Grotha*		*per conference call

Topics	Discussion/Action
<u>Call to Order</u>	<ul style="list-style-type: none"> ▪ Degnin called the meeting to order at 1:03. ▪ Roll call attendance was taken – quorum is present.
<u>Approval of July 2013 and July 2014 minutes</u>	<ul style="list-style-type: none"> ▪ Motion to accept July 19, 2013 and July 18, 2014 (edited) minutes made by Sheffield; second by Small. Minutes approved.
<u>Announcements</u>	<ul style="list-style-type: none"> ▪ Piper – Marcus Johnson-Miller is the new Bureau Chief for the Bureau of Family Health. CCID belongs to this bureau. Brenda Dobson is the interim Division Director for the Division of Health Promotion and Chronic Disease Prevention, which includes the BFH.
<u>Membership</u>	<p>New members were introduced and told a little bit about their backgrounds. All new members are awaiting formal appointment by the director of IDPH, Gerd Clabaugh, but are able to serve on the committee pending appointment.</p> <p>CIDAC Members rotating off the committee were thanked for their service, and will receive a certificate of appreciation from Director Clabaugh.</p>
<u>Elect Chair and Vice Chair/Chair Elect</u>	<p>Traditionally, the vice chair/chair elect assumes the position of committee chair when the chair's term expires. Kari Atkinson, current vice chair, does not feel comfortable assuming the role of chair at this time. Dr. Francis Degnin has stated his willingness to serve another term as chair, pending CIDAC approval. We would then nominate and elect a new vice chair/chair elect. Sheffield moved that Dr. Degnin extend his term as chair. Romitti seconded. Vote = Motion carried. Dr. Degnin will serve another term as chair. Dr. Sandy Daack-Hirsch stated she would be willing to serve as vice chair/chair elect. Sheffield moved that Dr. Daack-Hirsch be elected vice chair/chair elect of CIDAC. Romitti seconded. Vote = Motion approved, Dr. Daack-Hirsch will serve as CIDAC vice chair/chair elect.</p>
<u>Administrative Rules update</u>	<p>Piper reviewed the amended notice of intended action that will form the basis for the rules to be adopted at the State Board of Health meeting on November 12, 2014. The SBOH meeting is open to anyone</p>

	<p>who wishes to attend. It is at the Iowa Department of Public Health on November 12, starting at 10:00 am. Address: 5th Floor Conference Rooms 517/518 321 E. 12th Street Lucas State Office Building Des Moines, IA 50319</p> <p>Piper summarized the public comments received during both public comment periods, and indicated that those comments will also be summarized in the file for adoption. (see attached)</p>
<p><u>Subcommittee Reports</u></p>	<ul style="list-style-type: none"> • Romitti – the Use of Residual Newborn Screening Specimens subcommittee has drafted a policy (attached) to provide direction for the storage, retention, and use of residual specimens. Discussion was held about the policy. • Daack-Hirsch – The Informed Consent subcommittee has its work cut-out for them. A lot of the Informed Consent subcommittee’s work is based on the residual specimen subcommittee’s work. Many scenarios for obtaining informed consent for the use of residual NBS specimens for research have been explored. Have to consider who should have the responsibility for informing, and collecting/submitting the consent forms. Timing of the consent was discussed. Education of providers has been discussed. Until resources are available to not only develop but sustain the storage and management of a consent process for residual NBS specimens, we are not sure we can proceed. Much discussion from the committee. • Holida – Myrl Holida provided information about lysosomal storage disorders to the committee. The subcommittee looking at the addition of LSDs to Iowa’s newborn screening panel. Subcommittee members are researching the potential conditions, prioritizing the conditions with available testing methods and treatments. • Through discussions held at the first LSD subcommittee meeting, it was determined that a standing CIDAC subcommittee is warranted to develop a process and policy for determining whether a condition should be added to the panel. Sheffield moved the establishment of a subcommittee to develop a policy for the addition of conditions to Iowa’s NBS panel. Romitti seconded. Vote = approval of establishment of a standing subcommittee. Members volunteering to serve on this subcommittee - ?
<p><u>Status of Karpen/Shankar proposal to use residual NBS specimens for biliary atresia screening</u></p>	<p>Piper reviewed Dr. Karpen’s presentation from the last CIDAC meeting. Many members had to sign off the call before the presentation was finished. The CIDAC at that time asked that Piper establish a survey of members to indicate their approval of the premise of the research to allow Karpen/Shankar to communicate with the SHL and the IRCID to determine the feasibility of the proposal. A majority of members approved the proposal’s premise. Piper will draft an approval letter to Drs. Karpen and Shankar for Degrin’s signature on behalf of CIDAC. Drs. Karpen and Shankar will then be expected to submit a final proposal to CIDAC prior to proceeding with the use of residual NBS specimens.</p>
<p><u>Use of Newborn Screening Fees/Developmental Funds to Develop Integrated Newborn</u></p>	<p>Piper presented information on the development of the new Newborn Screening Information System (INSIS). Through an RFP process, OZ Systems, Inc. was awarded a contract to build a data system that will integrate hearing, dried blood spot, and CCHD newborn screening information into one data system. Funding for the INSIS comes from</p>

<u>Screening Data System</u>	Medicaid matching funds, other relevant state funds for data system's development, and newborn screening fees/developmental funds. IDPH fiscal staff have asked for documentation of CIDAC's approval to use newborn screening fees to support the INSIS. Members present asked for a specific summary of the INSIS project and a listing of project funding. Piper will provide documentation about the INSIS, and post to a survey for CIDAC members to indicate approval for use of NBS fees for the INSIS.
<u>Future meeting schedule</u>	The next meeting will be January 23, 2015 via conference call over the noon hour. A poll of CIDAC members indicated that Friday meetings were still preferred, add another face-to-face meeting, and increase the length of the conference call meetings to up to two hours. Piper is considering having one call per year occur during evening or weekend hours to enable families and other members to participate.
<u>Adjournment</u>	Meeting adjourned at 3:15 pm.