

July 18, 2014

12:00 p.m.

# CIDAC Meeting

Conference Call

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<b>Meeting called</b>	Francis Degnin	<b>Type of</b>	CIDAC
<b>Facilitator:</b>	Kimberly Piper	<b>Note taker:</b>	Kimberly Piper

**Attendees:** Sandra Daack-Hirsch; Chris Atchison; Stanton Berberich; Francis Degnin; Paul Romitti; Val Sheffield; Kelly Schulte; Cathy Evers; Lori Murphy-Stokes; Myrl Holida;

**Absent:** Kari Atkinson; Merida Miller; Lori Murphy-Stokes; Roger Williamson; Bryon Schaeffer; Jeff Murray; Michelle Gogerty; Alison Heffern

**Others in Attendance:** Carol Johnson; Tammy O'Hollearn; Heather Adams; Saul Karpen; Prabhu Shankar; Kimberly Piper

**Quorum present at 12:05**

## Minutes

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<b>Agenda item:</b>	Roll call attendance	<b>Presenter:</b>	Kim Piper
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**Discussion:**

Quorum present after 5 minutes into meeting. Agenda was adjusted to allow quorum vote.

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<b>Agenda item:</b>	Approval of Minutes	<b>Presenter:</b>	Francis Degnin
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**Discussion:** Amendment to October 2013 minutes to indicate Stan Berberich's absence. Motion – Daack-Hirsch, 2<sup>nd</sup> Sheffield – Minutes October 2013 (as amended) and January 2014 approved. Piper will provide July 2013 minutes for review prior to October 2014 meeting. April 2014 meeting was cancelled due to Good Friday.

<b>Action items</b>	<b>Person responsible</b>	<b>Deadline</b>
✓ Minutes posted to CCID Web site	Piper	8/1/2014

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<b>Agenda item:</b>	Announcements	<b>Presenter:</b>	Members/guests
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**Discussion:** Kim Piper stated that she is looking for feedback for how to increase attendance and participation in CIDAC discussions, especially from consumers and family members/patients. Piper will send a poll out to members to vote for preferred meeting dates, times and formats. Piper wants members to feel like this is a valuable use of their time and that their participation is respected.

<b>Action items</b>	Posting and email link to poll.	<b>Person responsible</b>	Piper	<b>Deadline</b>	8/1/2014
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**Agenda item:** Membership **Presenter:** Kim Piper

**Discussion:** Several members' terms have expired or they have been unable to attend meetings (refer to Roster). Please let Piper know if you wish to extend your term, or have suggestions for new members to nominate for vacant positions. New members will begin with the October meeting. Kari Atchison will also begin her term as CIDAC chair at the October meeting.

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**Action items** Nominate individuals for open positions **Person responsible** CIDAC **Deadline** 9/1/2014  
Members

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**Agenda item:** Consent for Use of Residual Newborn Screening Dried Bloodspot Specimens **Presenter:** Heather Adams

**Discussion:**

Piper stated that the Iowa Newborn Screening Program was moving toward a process of informed consent for use of residual specimens for research purposes. Currently parents/guardians may send a letter to the SHL requesting the specimens not be released for research. As discussed at previous meetings, Chapter 4 of the Iowa Administrative Rules is being amended to reflect this change. Heather Adams presented information regarding the legal issues surrounding use of residual specimens for research; other states' experiences, specifically the lawsuits in Texas and Minnesota; and the reasons Iowa is making this change.

Waldron: Applaud these efforts

Daack-Hirsch: A proponent of the consent process. There are many tools to help manage the consent process.

Degnin: Confident that it won't significantly impact newborn screening or the availability of specimens for research, based on discussions at the Public Health Law Institute's Uses of Residual Dried Blood Spot meeting the he attended last October.

Waldron: Important to remember that main purpose is newborn screening. Research is secondary.

Romitti: Agrees with informed consent process. Concerns with lack of defined process for how this will be implemented. Need face-to-face-meeting to develop procedure.

Berberich: According to January 2013 CIDAC minutes, this was supposed to be addressed starting in early 2013. This was also discussed at subsequent meetings, but nothing has happened. Need to define timeline, action steps, and persons responsible.

Piper: Has not had time to address this (apology), and had difficulty recruiting individuals to address this.

Daack-Hirsch: This needs a thoughtful process, but needs to move forward.

Romitti volunteers to lead subcommittee to develop a procedure.

Adams/Piper: Is there consensus on the issue of informed consent?

Committee members: Yes

Sheffield: Perhaps we should table the rules for informed consent.

- Stated as motion at request of Chair – Move to table the amended administrative rules for informed consent due to concerns with lack of implementation procedure.

Romitti 2<sup>nd</sup>

Roll-call vote – Motion carried

**Action Item:** Piper will convene subcommittee to develop informed consent process. Adams, Piper and IDPH administrative rules coordinator will discuss "tabling" of administrative rules.

**Person Responsible:** Piper

**Deadline:** 8/1/2014

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**Agenda item:** Research Proposal Potential Test Development for Newborn Screening for Biliary Atresia **Presenter:** Drs. Saul Karpen and Prabhu Shankar

**Discussion:**

Dr. Karpen presented background and proposed use of residual dried blood spot specimens to investigate the feasibility of using newborn screening for early detection of neonatal cholestasis, biliary atresia and related conditions. [Research proposal and PowerPoint presentation made available to members prior to meeting.]

[Berberich, Atchison and Romitti leave for another meeting at 1:05. No longer have quorum.]

Drs. Karpen and Shankar intend to test their hypothesis that certain bile acids measured in DBS are:

- Reliable markers to identify patients with BA and
- Differentiate BA from other causes of cholestasis and controls

Since there is no longer a quorum present, it was recommended that Piper send out a message to CIDAC members requesting their recommendation to proceed with advancing this proposal. Drs. Karpen and Shankar would work with the SHL and the IRCID to identify potential research subjects and availability of residual specimens and data.

**Action Item:** Piper will provide a link to a poll of CIDAC members where they can indicate their approval of this proposal.

**Person Responsible:** Piper and CIDAC Members

**Deadline:** 9/1/2014

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**Agenda item:** Next Meeting and Adjournment

**Discussion:** Next CIDAC Meeting will be in-person meeting in Grinnell, Iowa on Friday, October 24 from 1:00 to 3:30 pm.

**Meeting Adjourned at 1:19pm**