Members Present | Members Absent | Others Present
---|---|---
Sandra Daack-Hirsch | Paul Romitti | Kimberly Noble Piper
Brenda Walker | Sara Dricken | Emily Phillips
Roger Williamson | Michelle Gogerty | Carol Johnson
Merida Miller | Senator Ragan* | Alvaro Serrano
Lori Murphy-Stokes | Representative Wessel | Stacy Frelund
\[\text{Others Present}\]
Cathy Evers | Bryon Schaeffer | Aileen Baldwin
Debra Waldron | Douglas Lewis | Kelly Schulte
Stan Berberich | | Kari Atkinson
Francis Degnin | |
Alison Heffern | |
Becky Lutgen Gardner | |
Val Sheffield | |
Jeff Murray | *Honorary positions | *

**Topics** | **Discussion/Action**
---|---
**Call to Order** | Kim Piper called the meeting to order. In light of the pending appointments to membership and officer positions, Ms. Piper will facilitate the meeting. Introductions of new members were made. Roll call attendance = quorum present.

**Approval of April 20, 2012 and October 12, 2012 Minutes** | Motion to accept amended April minutes and October minutes as written made by Degnin; second by Daack-Hirsch. Roll call vote = motion carried.

**Announcements** | Johnson - U of I has given the Division of Medical Genetics permission to recruit 2 new geneticists. Sheffield – permission one at a time. Ad was published. Members are asked to contact Carol Johnson of they know of a beneficial recruitment venue.

| **CCHD bill SSB 1001 was introduced Monday January 14. Assigned to the Human Resources subcommittee. Bill requires IDPH to assure Iowa birthing hospitals are screening all newborns for critical congenital heart disease using pulse oximetry. Piper will send a copy of the bill to committee members.** |

**Membership and Appointments update** | Piper has contacted Director Miller-Meeks' office and her assistant is making appointments to the committee. There are two nominees waiting official appointment, and one organization, the Iowa Osteopathic Medical Association, will be forwarding a nominee after their next membership meeting. Then all positions will be filled. There is not a limit on the number of parent/affected individual members, as long as total committee membership is ≤ 25 members.
### Election of Officers for FY2013
- Piper has explained the duties and responsibilities of the positions of chair and vice chair (chair-elect). Nominations for chair and vice chair were solicited. Degnin volunteers for the chair position, and Atkinson volunteers for the vice-chair position pending her official appointment to the committee. Heffern moves to elect Degnin to chair, and Atkinson as vice chair. Walker seconds. Roll call vote = Degnin elected as Chair of CIDAC, and Atkinson elected Vice Chair (chair elect), pending her appointment.
- Degnin has asked Piper to continue to facilitate this meeting, as he is not as familiar with the agenda.

### SCID Update and request for Developmental Funds
- Dr. Stan Berberich: The lab is in the midst of a blinded pilot screening 3000 newborns to determine TREC (assay) cut-offs. The CDC is sending materials to test assay proficiency. An implementation pilot will begin after this blinded pilot. Results of SCID screening will not be provided to families/providers unless an abnormal result is seen; in that case the short-term follow up staff will follow up with the primary care provider.
- Carol Johnson: Screening and follow up algorithms continue to be finalized by Dr. Fasano, Emily Phillips, Dr. Ferguson, Carol Johnson, Stan Berberich, and Lucy Desjardin.

### NBS Budget update
- The NBS budget will be re-evaluated after the SCID pilot, and will incorporate the fee increase.

### Proposal
- Dr. Aileen Baldwin and Dr. Douglas Lewis presented their research proposal: “Newborn Screening for Prenatal Alcohol Exposure in the Iowa Population; Detection of the Direct Alcohol Biomarker Phosphatidylethanol in Residual Dried Blood Spot Specimens”
- Proposal included a request for use of anonymized residual dried blood spot specimens from the newborn screening program.
- Discussion with questions and answers was held.
- Heffern made a motion to recommend IDPH approves release of residual dried blood spot specimens for this research study as outlined in the research proposal. Degnin seconded.
- Roll call vote 10 ayes, 3 nays = motion carried.
- Piper will draft a letter to Dr. Baldwin for Dr. Degnin’s signature on behalf of the committee. Next step is presentation to the IDPH Ethics Review Committee.

### IAC
- Chapter 641 IAC 4 “Center for Congenital and Inherited Disorders” has been noticed for amendments. The State Board of Health was notified of the intent to amend the rules at the meeting on January 9th. Next steps are a notice to the Legislative Administrative Rules Committee and a public comment period. Written public comments are now being accepted until February 12, 2013. A public comment conference call will be held February 12, 2013 from 10:00 to 11:00 am, at which time comments will be accepted. Please see the Notice of Intended Action for details of the changes and call-in information for the public comment call.

### Call for members of ad hoc work groups
- There will be two ad hoc work groups forming. One will be examining the storage and use of residual dried blood spot and maternal serum specimens, and the other will address the “waiver for research use of screening biospecimens” process. If you are interested on serving on either of these committees, please let Piper know.
| Agenda items for next meeting April 19 via conference call | Strategic planning  
Ad hoc committee reports |
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<td><strong>Adjournment</strong></td>
<td>Meeting adjourned at 1:03 pm.</td>
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