Iowa Congenital and Inherited Disorders Advisory Committee
Grinnell, Iowa
July 15, 2011
1:00 p.m. – 4:00 p.m.

Minutes

Members Present
Shelley Ackermann
Kristi Borowski
Paul Romitti
Sandra Daack-Hirsch
Nancylee Ziese
Catherine Evers
Francis Degnin
Stanton Berberich
Roger Williamson
Bryon Schaeffer
Becky Lutgen Gardner

Members Absent
Kori Ensley
Brenda Walker
Gregory Garvin
Debra Waldron
Val Sheffield
Diana Hoogestraat
Gayle Culbertson
Michelle Gogerty
Alison Heffern

Others Present
Kimberly Noble Piper
Carol Johnson
Dr. Mary Larew
Dr. Barbara Stegmann
Anne Crotty

Senator Amanda Ragan**
Representative Beth Wessel Kroshell**
** Honorary Members

Topics

Call to order
Dr. Kristi Borowski called the meeting to order at 1:12 pm.
Introductions were made, and two new members – Becky Lutgen Gardner and Dr. Bryon Schaeffer - were welcomed.
A quorum is present.

Minutes of April meeting
Motion by Schaeffer to approve the April minutes, second by Ziese.
Minutes approved as written, pending correction of spelling of Dr. Serrano Russi’s name.

Announcements
Johnson: Dr. Alvaro Serrano-Russi is a new medical geneticist that started this last Monday (July 11). He and dr. Oleg Shchelochkov will be taking their biochem boards this fall.
Johnson: Dr. Greg Rice, a biochem geneticist and director of Wisconsin’s newborn screening program, is coming for a recruiting visit later this month. He would be hired as the medical director of Iowa’s dried blood spot newborn screening program.
Johnson: a child that was diagnosed with MMA four years ago by Iowa’s program just received a liver and kidney transplant, and is doing well. Good to hear of these great outcomes! Kudos to the screening program and follow up staff!
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<th><strong>Election of Officers</strong></th>
<th>The process of succession for the seat of committee chair and term lengths were discussed. Ziese moved that Dr. Greg Garvin and Dr. Kristi Borowski continue as chair and vice chair, respectively. Evers seconded the motion. Motion approved.</th>
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<td><strong>Membership terms</strong></td>
<td>Four members’ terms have expired: Cathy Evers, Alison Heffern, Francis Degnin, and Sandra Daack-Hirsch. Evers will talk to her cohorts in the clinical genetics area to see if they want to take the position. Degnin and Daack-Hirsch are both willing to serve another term. Piper will speak with Heffern about serving another term.</td>
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<td><strong>Bylaws vs. CIDAC charter</strong></td>
<td>Piper states that the assistant attorney general recommends that legislated committees do not use bylaws. The option is to have guidance for the CIDAC in administrative code, or use a charter to provide direction for the committee. Piper has provided a draft of a charter for members to review. Degnin and Ziese volunteered to assist with editing of the charter with feedback from the committee members. A revised draft will be available to members for the next meeting in October.</td>
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<td><strong>Research proposal</strong></td>
<td>Dr. Barbara Stegman presented a proposal to use residual maternal serum screening specimens for a research study for markers of potential preterm birth. Dr. Stegman will use aliquots from Dr. Borowski’s research. Discussion was held about disposition of residual aliquots and if IRB approval was needed. Berberich recommended that if IDPH approves proposal, approval letter should be specific about disposition of residual aliquots. Motion from Ackermann to recommend IDPH approval of the proposal and use of residual maternal serum specimens. Evers seconded. Motioned passed.</td>
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<td><strong>SCID update</strong></td>
<td>Berberich provided an update on the application for funding for a SCID pilot. No word yet about a funding award, however the application did pass the initial technical review. Iowa will start pilot screening for SCID in September. A work group is being organized by Kim Turner to address planning for the pilot screening and follow up system.</td>
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<td><strong>CCCHD newborn screening</strong></td>
<td>The Secretary’s Advisory Committee on Heritable Disorders in Newborn and Children has recommended to Secretary Sebelius that Critical Congenital Cyanotic Heart Disease be added to states newborn screening panels. Secretary Sebelius has taken the recommendation under advisement, and will make a decision about the recommendation soon. Piper is establishing a work group to review the recommendation and decide how screening for CCCHD would best be implemented in Iowa. Screening for CCCHD would be very different from dried blood spot screening. It would be hospital based, using various quality of hospital equipment, no monitoring or data collection system, and no follow up system in place.</td>
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<td><strong>Use of residual newborn dried blood spots</strong></td>
<td>There is a work group addressing the issue of informed “opt out” for use of residual dried blood spots for research purposes. The group has discussed many options for obtaining the opt out signature and the timing of the education to parents about their options. The work group will have a draft policy ready for presentation to the committee at the next meeting. The policy will be combined with the existing storage, retention and use of residual dried blood spot policy. A policy for use of residual maternal serum specimens will be drafted parallel to the DBS policy.</td>
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| Agenda items for next meeting October 14, 2011 via conference call | Program annual reports  
Review sustainability planning  
Needs assessment  
Policy/Procedure update  
Status of SCID pilot/CCCHD screening planning/ Use of residual DBS/maternal serum for research policy |
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<td>Adjournment</td>
<td>Meeting adjourned at 3:05 pm.</td>
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