Minutes

The regular meeting of the Iowa Congenital and Inherited Disorders Advisory Council was held July 24, 2009 at the Wells Fargo Bank Building, Grinnell, Iowa.

Members Present

Roger Williamson, MD
Sara Copeland, MD
Paul Romitti, PhD
Nancy Lee Ziese
Catherine Evers, RN, MA
Jerry Wickersham
Stanton Berberich, PhD
Robert Shaw, MD
Jessica Phillips
Debra Waldron, MD
Kristi Borowski, MD
Sandra Daack-Hirsch, PhD
Brenda Walker

Members Absent

Shelley Ackermann, LISW
Francis Degnin, PhD
Senator Amanda Ragan**
Representative Beth Wessel
Gregory Garvin, DO
Lisa Mofle, MD
Paul Romitti, PhD
Alison Heffern, JD
Becky/James McIlrath
Kori Ensley
Stacey Montgomery

Others Present

Kimberly Noble Piper
Carol Johnson
Kelli Ryckman, U of I

** Honorary Members

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<tr>
<th>Topics</th>
<th>Discussion/Action</th>
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<td>Call to order</td>
<td>• Wickerson called the meeting to order at 1:13 p.m.</td>
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<td>• Members and guests introduced themselves.</td>
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<td>Minutes of April meeting</td>
<td>• Motion to approve the minutes as amended by Ziese, second by Copeland.</td>
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<td>• Approved</td>
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<td>Announcements</td>
<td>• Carol Johnson = Medical Geneticist recruiting – Dr. Oleg Shchelochkov starts November 2nd. September 1, Dr. Pamela Trapano, medical geneticist, begins working.</td>
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<td>• Carol Johnson = Dr. Marcia Willig has resigned, her last day is today.</td>
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<td>Election of Officers</td>
<td>• Copeland nominated Jerry Wickersham for Chair.</td>
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<td>• Nominations closed.</td>
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<td>• Vote – Jerry Wickersham elected as incoming Chair.</td>
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<td>• Kristi Borowski nominated for Vice Chair by Copeland.</td>
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<td>• Nominations closed.</td>
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<td>• Kristi Borowski elected incoming Vice Chair.</td>
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| **New Member Welcome** | • The Committee welcomed new members.  
• The value of participation on this committee was supported by long-term members. |
| **IDPH Update** | • Budget revenue estimating conference in October will probably influence funding levels for the second half of SFY10 and next SFY2011.  
• Discussion about discretionary grants |
| **Retention and Use of residual blood** | • Committee for Consent, Storage and Use of Residual DBS specimens  
• Piper provided information regarding the attention being given at the national level regarding the consent of parents for the storage and use of the newborn’s residual dried blood spot specimen. MN is being sued by a group to assure residual specimens are not stored without express consent of the parents.  
• The American College of Medical Genetics has a grant to address this issue at the national level.  
• Piper recruits membership to an ad hoc committee to develop a comprehensive policy and procedure for the consent, storage and use of residual specimens.  
• Those expressing interest are Ziese, Shaw, Culbertson, and Heffern. It was suggested that members of the committee that established the current policy be included, as well as Dr. Jeff Murray, Dr. Degnin, and Dr. Christian Simons.  
• Piper will convene a meeting after speaking with Heather Adams, the Assistant Attorney General.  
• Piper solicits contributions of any literature or materials that enable the committee, as well as additional membership, especially parents/consumers. |
| **Research Proposal using DBS and data points from newborn screening** | • Dr. Kelli Ryckman presented a proposal “Investigation of Genetic and Environmental Factors that Impact Variation in Enzymes and Metabolites from the Iowa Newborn Screen.”  
• Request to obtain data points and residual DBS specimens, and letter of support from CIDAC was made by Copeland and Ryckman.  
• Shaw moved, Walker seconded.  
• Piper will draft a letter of support for Wickersham’s sig.  
• Ryckman will present study reports to CIDAC.  
• CIDAC would also like to request that any approved research proposal provide a presentation of results prior to publication or dissemination. |
| **Administrative Code updates 641 IAC 4** | • Piper stated that the Congenital and Inherited Disorders chapter of administrative rules (641 IAC 4) has been adopted and filed.  
• Rules are effective September 1, 2009. |
| **Program Updates** | • Johnson – update about new advisory committee for metabolic formula and food. Two consumers now on committee. Discussed allocation of state appropriation to metabolic program “members.”  
• Copeland – NBS short-term follow-up program has kicked into high gear; regular QA meetings, educational efforts, and organizational work is occurring  
• Berberich – The lab is now routinely running screening tests for the two markers using the new technology as previously approved by CIDAC. UHL has regular contact with David Wright in UK |
(patent holder of repeat maternal testing technology); looking to obtain permission to use technology to decrease false positive rates. In the process of projecting a budget, and will have for next meeting. Unlike the DBS storage, the UHL does not have the facilities to store maternal serum specimens long term. Have not seen a large increase in uptake of women/providers ordering the integrated screening. Perhaps an educational effort to an expanded targeted population would help. Williamson – the private labs are still in the door promoting use of their company, and providers do not understand the law that requires maternal serum specimens be sent to the UHL. Culbertson – there is the perception that the UHL is much more expensive – even though costs are bundled, and no comparison of apples and apples. Williamson – two options = new mailing that touts new repeat screening and the “lowest false positive rate” that it provides, or have a letter from the state reminding agencies of Iowa Code and Administrative Rules.

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<th>Lobbying/public affairs</th>
<th>Jessica Phillips leads a discussion/presentation about program advocacy.</th>
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| **Agenda items next meeting/next meeting dates** | Program annual reports  
Review State Plan status  
Needs Assessment  
Policy/Procedure Update  
Discussion about moving meeting time up to a noon start – members in attendance approved, but others may not be able to attend at the earlier start time due to clinical responsibilities. |
| **Adjournment** | Motion to adjourn by Copeland, second by Walker.  
Meeting adjourned at 3:20 pm. |