The regular meeting of the Iowa Congenital and Inherited Disorders Advisory Council was held August 20, 2004 at Stewart Public Library, Grinnell, Iowa.

<table>
<thead>
<tr>
<th>Members Present</th>
<th>Members Absent</th>
<th>Others Present</th>
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<tbody>
<tr>
<td>Roger Williamson, MD</td>
<td>Shelley Ackermann, LISW</td>
<td>Kimberly Noble Piper</td>
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<tr>
<td>Francis Degnin, PhD</td>
<td>Sara Copeland, MD</td>
<td>Carol Johnson</td>
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<tr>
<td>Paul Romitti, PhD</td>
<td>Senator Amanda Ragan**</td>
<td>Barb Schweitzer</td>
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<tr>
<td>Nancylee Ziese</td>
<td>Representative Beth Wessel</td>
<td>Marcia Valbracht</td>
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<tr>
<td></td>
<td>Kroschell**</td>
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<tr>
<td></td>
<td></td>
<td>Kimberley Turner</td>
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<tr>
<td></td>
<td></td>
<td>Gunderson (Student)</td>
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<tr>
<td>Catherine Evers, RN, MA</td>
<td>Gregory Garvin, DO</td>
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<tr>
<td>Jerry Wickersham</td>
<td>Kristi Borowski, MD</td>
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<tr>
<td>Stanton Berberich, PhD</td>
<td>Sandra Daack-Hirsch, PhD</td>
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<tr>
<td>Lisa Mofle, MD</td>
<td>Robert Shaw, MD</td>
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<tr>
<td>Jessica Phillips</td>
<td>Debra Waldron, MD</td>
<td></td>
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<tr>
<td>Alison Heffern, JD</td>
<td>Patti Rawson, LISW, ACSW</td>
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<td></td>
<td>Blythe Stanfel</td>
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<td></td>
<td>Tiffan Yamen</td>
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** Honorary Members

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<tr>
<th>Topics</th>
<th>Discussion/Action</th>
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| Call to order | ▪ Dr. Mofle called the meeting to order at 1:05 p.m.  
▪ Members and guests introduced themselves. |
| Minutes of January meeting | ▪ Motion to approve the minutes by Wickersham, second by Williamson.  
▪ Approved 9 – 0 with Degnin abstaining, as he was unable to read the minutes due to formatting issues. |
| Announcements | ▪ Carol Johnson = Medical Geneticist recruiting – Dr. Shchelochkov. is still interested, working on Visa issues; two more recruits, one coming for a second visit, and another for a first visit. Recruiting for the Department of Neurology on hold due to budget constraints.  
▪ Carol Johnson = University programs suffered budget cuts of 13.3%. University staff also asked to consider voluntary cuts (no vacation pay, furloughs, etc.) |
| IDPH Update | ▪ The legislature has yet to finish budget and appropriation bills. It is expected that there will be significant budget reductions required for fiscal year 2010. We will know more once the session adjourns.  
▪ Discussion about program advocacy was held. Suggestions |
included having a lobbying/advocacy presentation to the committee at the next meeting; need to promote programs throughout the year, not just during legislative session; develop DVD or materials with personal stories to share with legislators; and using opportunities to capitalize on program awareness, such as television reporter’s pregnancies, etc.

- Jessica Phillips will present advocacy/lobbying session to the committee at the next meeting
- Piper is coordinating/writing applications for three discretionary grants.

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<thead>
<tr>
<th>Retention and Use of residual blood spot specimens for Pyloric Stenosis research</th>
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<tr>
<td>Dr. Romitti presented a proposal to use residual BS specimens for a research proposal.</td>
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<tr>
<td>Motion to approve proposal made by Ziese, second by Evers</td>
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<td>Vote 9-0 with Romitti abstaining. Motion carries</td>
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<tr>
<th>Code of Ethics</th>
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<tr>
<td>Dr. Degnin presented the revised Code of Ethics</td>
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<tr>
<td>Wickersham moved to approve Code of Ethics, second by Phillips</td>
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<td>Vote 10-0. Motion carries.</td>
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<tr>
<th>Review of Program Annual Reports</th>
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<tr>
<td>Committee members had received the annual reports prior to the meeting. No questions were posted.</td>
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<td>Metabolic formula/medical food report was missing from the comprehensive report. This will be posted to the CCID Web page.</td>
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<tr>
<th>Administrative Code updates 641 IAC 4</th>
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<tr>
<td>Piper stated that the Congenital and Inherited Disorders chapter of administrative rules is open for amendments</td>
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<tr>
<td>Main reason for opening rules is to indicate increase to metabolic screening fee.</td>
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<tr>
<td>Discussion held as to budgeting for increase in testing for second and third screens for sick/premature neonates.</td>
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<th>New member nomination</th>
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<tr>
<td>Positions open: Iowa Academy Family Physicians (Dr. Mofle); Consumer representative x 2 (Nancy Lee Ziese and vacant); Parent representatives x 2 (Blythe Stanfel &amp; Tiffan Yamen); Iowa Osteopathic Medical Association (Dr. Garvin).</td>
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<tr>
<td>Please submit nominations for these positions to Piper as soon as possible.</td>
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<tr>
<td>Dr. Mofle will continue as the Iowa Academy of Family Physicians representative</td>
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<td>Piper recommends adding four parent representative positions to the committee. Members were in agreement with this.</td>
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<tr>
<th>Agenda items next meeting/next meeting dates</th>
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<tr>
<td>New member welcome/orientation</td>
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<td>Out-going member recognition</td>
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<td>Expenditure report preview</td>
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<tr>
<th>Adjournment</th>
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<tr>
<td>Motion to adjourn by Wickersham, second by Heffern</td>
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