CIDAC Meeting

Meeting called by: Lisa Mofle  
Type of meeting: CIDAC

Facilitator: Kim Piper  
Note taker: Kim Piper

Dr. Bradley McDowell, Iowa Registry for Congenital and Inherited Disorders; Dr. Roger Williamson, OB/GYN U of I; Shelley Ackermann, Dept. of Education; Dr. Lisa Mofle, Family Practice; Stan Berberich, UHL; Dr. Robert Shaw, Iowa American Academy of Pediatrics, Dr. Sandra Daack-Hirsch, Iowa Nurses Association; Dr. Francis Dominic Degnin, UNI Bioethicist; Jerry Wickersham, Iowa Insurance Division; Cathy Evers, Clinical Services U of I; Allison Heffern, Attorney; Dr. Paul Romitti, U of I College of Public Health; Dr. Kristi Borowski, Iowa American College of Obstetricians and Gynecologists; Dr. Greg Garvin, DO

Attendees:

- Dr. Bradley McDowell, Iowa Registry for Congenital and Inherited Disorders
- Dr. Roger Williamson, OB/GYN U of I
- Shelley Ackermann, Dept. of Education
- Dr. Lisa Mofle, Family Practice
- Stan Berberich, UHL
- Dr. Robert Shaw, Iowa American Academy of Pediatrics
- Dr. Sandra Daack-Hirsch, Iowa Nurses Association
- Dr. Francis Dominic Degnin, UNI Bioethicist
- Jerry Wickersham, Iowa Insurance Division
- Cathy Evers, Clinical Services U of I
- Allison Heffern, Attorney
- Dr. Paul Romitti, U of I College of Public Health
- Dr. Kristi Borowski, Iowa American College of Obstetricians and Gynecologists
- Dr. Greg Garvin, DO

Absent:

- Patti Rawson, Social Worker
- Dr. Debra Waldron, UIHC, CHSC
- Dr. Sara Copeland, Division of Medical Genetics
- INMSP Medical Director
- Senator Amanda Ragan
- Representative Beth Wessel Kroeschell
- Blythe Stanfel, parent
- Christopher Atchison, UHL
- Representative, Volunteer Agency, March of Dimes
- Tiffan Yamen, parent
- Nancylee Ziese, Consumer

Others in Attendance:

- Carol Johnson, UIHC
- Judy Miller, UIHC
- Dr. Val Sheffield, UIHC
- Christina Trout, UIHC
- Pam DeBoer, UIHC
- David Stoltz, UIHC
- Dr. Debra Kane, IDPH
- Marcia Valbracht, UHL

Quorum present

Minutes

Agenda item: Introductions

Presenter:

Discussion:

Roll call was taken. Members and guests introduced themselves and the organization they represent.

Agenda item: Approval of Minutes

Presenter: Lisa Mofle

Discussion:

Minutes approved as written.

Action items

<table>
<thead>
<tr>
<th>Person responsible</th>
<th>Deadline</th>
</tr>
</thead>
<tbody>
<tr>
<td>Piper</td>
<td>04/01/2009</td>
</tr>
</tbody>
</table>

Agenda item: Announcements

Discussion:

Johnson - Faculty recruiting. A medical geneticist is being recruited, and the University is currently working with the IDPH to obtain a waiver for his J1 Visa. He is from Uzbekistan, and completed his residency at the U of I, and his fellowship at Baylor. Dr. Loew will be leaving the hemoglobinopathy program in May.

Agenda item: IDPH/CCID/update

Discussion:

Governor Culver has implemented a 1.5 percent across the board budget cut for all departments, with the exception of public safety. Governor Culver's proposed budget for FY2010 includes an additional 6-10 percent reduction. No genetics programs are thought to be eliminated, however, there is the potential for funding reductions.
Agenda item: Code of ethics

Discussion: The committee reviewed a draft code of ethics prepared by Dr. Degnin. Changes were recommended. The document will be edited to include recommended changes, and presented for approval at the next meeting.

Action items

<table>
<thead>
<tr>
<th>Action items</th>
<th>Person responsible</th>
<th>Deadline</th>
</tr>
</thead>
<tbody>
<tr>
<td>Edit document to incorporate recommended changes</td>
<td>Piper</td>
<td>April 1, 2009</td>
</tr>
</tbody>
</table>

Agenda item: Research proposal for use of residual blood spot specimens

Discussion:

Dr. Stoltz presented a proposal “Use of Newborn Screening Samples to Test for Insulin-like Growth Factor 1 (IGF-1) in Cystic Fibrosis. Study aims to examine the correlation between IGF-1 and complications of cystic fibrosis. Discussion held.

Motion to approve use of residual specimens: Mofle; Second: McDowell Vote: Aye 14, Nay 0. Motion carried.

Agenda item: Newborn Screening Budget/Fee Increase

Discussion:

A proposed budget for SFY2010 (and the next three years) was presented. A fee metabolic screening increase from $97 to $110 is proposed to allow for anticipated cost-of-living, and courier expenses (fuel, etc.). Discussion held.

Motion to recommend that IDPH approve the new budget and fee increase was made by Wickersham. Seconded by Shaw. Vote: Aye 11; Nay 0; Abstaining 1 (Berberich). Motion carried.

Agenda item: Update to Iowa Administrative Code 641IAC4

Discussion:

Piper
Discussion:
The administrative rules for the genetics programs will be open for review and action. Members are asked to provide comments and suggested edits/updates to the rules. The rules need to be updated to reflect the fee increase.

<table>
<thead>
<tr>
<th>Action items</th>
<th>Send 641AC4 to members for review and comment.</th>
<th>Person responsible</th>
<th>Deadline</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Piper</td>
<td>March 1, 2009</td>
</tr>
</tbody>
</table>

Agenda item: Review program annual reports

Presentation: Piper

Discussion:
This item is deferred to the April meeting.

Agenda item: Bylaws review/update to include hemophilia advisory committee representation

Presentation: Piper

Discussion:
Discussion was held regarding to expand membership on the CIDAC to include representation of someone from the hemophilia/clotting disorder community.
Motion to expand membership: Garvin. Second: Daack-Hirsch. Vote: Aye 14; Nay 0; Motion carried.

Agenda item: Agenda items for next meeting – April 17th, 2009

Presentation: Mofle

Discussion:
Annual reports, ethics standards, bylaws, new member nominations, election of officers

Agenda item: Adjourn

Presentation: Mofle

Discussion:
Wickersham moved, Degrin second Adjourned 3:00 p.m.