CIDAC Meeting

Meeting called: Lisa Mofle
Type of: CIDAC
Facilitator: Kim Piper
Note taker: Kim Piper

Attendees: Dr. Sara Copeland, Division of Medical Genetics, INMSP Medical Director; Dr. Bradley McDowell, Iowa Registry for Congenital and Inherited Disorders; Dr. Roger Williamson, OB/GYN U of I; Nancylee Ziese, Consumer; Shelley Ackermann, Dept. of Education; Dr. Lisa Mofle, Family Practice; Patti Rawson, Social Worker; Stan Berberich, UHL; Dr. Robert Shaw, Iowa American Academy of Pediatrics, Dr. Debra Waldron, UIHC, CHSC; Dr. Sandra Daack-Hirsch, Iowa Nurses Association; Dr. Francis Dominic Degnin, UNI Bioethicist

Absent: Dr. Kristi Borowski, Iowa American College of Obstetricians and Gynecologists; Jerry Wickersham, Iowa Insurance Division; Senator Amanda Ragan; Representative Beth Wessel Kroeschell; Blythe Stanfel, parent.; Christopher Atchison, UHL; Representative, Volunteer Agency, March of Dimes; Dr. Greg Garvin, DO; Tiffan Yamen, parent; Cathy Evers, Clinical Services U of I; Allison Heffern, Attorney; Dr. Paul Romitti, U of I College of Public Health

Others in Attendance: Carol Johnson, UIHC; Leslie Thomas, UIHC; Dari Shirazi, UHL

Quorum present

Minutes

Agenda item: Introductions
Discussion:
Members and guests introduced themselves and the organization they represent.

Agenda item: Approval of Minutes
Presenter: Lisa Mofle
Discussion:
Change Louisa to Louisiana. Motion to approve minutes as amended: Copeland, Second: Ziese – motion carried.

Action items
 Person responsible Deadline

✓ Minutes posted to CCID Web site  Piper 01/01/2009

Agenda item: Announcements
Presenter: Members/guests
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.

Agenda item: IDPH/CCID/update
Presenter: Kim Piper
Discussion:
The state budget is forecasting a $500 million dollar shortfall. Governor Culver has not implemented any budget cuts at this time. A planned move to larger space for the Bureau of Family Health has been tabled.

Laurie Robison, program planner for the genetics program, resigned her position. Plans are to hire for that position.

### Action items

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<td><strong>Budget Update</strong> - Berberich/Copeland/Williamson - Costs are increasing. Looking at staffing requirements and required raises, reagent costs, testing methods, etc. Courier surcharge has increased 15% due to fuel costs. This will probably increase the screening fee for next year. Also seeing increasing costs on the follow-up side. The maternal integrated screening program will also require a fee increase. Will see a recommended increase in the screening fee for ’09-’10.</td>
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### Agenda item: INMSP purpose statement/Code of ethics

**Presenter:** Piper

**Discussion:**

The final draft of the INMSP purpose statement was approved as follows:

“The purpose of screening for metabolic and congenital disorders in the newborn period is to enable the early identification of, and intervention for, at-risk individuals. This will prevent or lessen adverse health consequences such as death, mental retardation, and serious illness, with the overall objective to improve the quality of life for Iowans.”

Motion to approve: Copeland; Second: Ziese All in favor – motion carries.

The committee requested that review and discussion of the Principles of Ethical Practice be tabled until the January meeting so members can review and get feedback from constituents.

### Agenda item: Use of NBS Developmental funds for equipment

**Presenter:** Berberich

**Discussion:**

Proposal to Add Succinylacetone Methodology to Early Detection of Tyrosinemia Type 1 was distributed. Tyrosine (currently used as marker) is not a reliable marker for Tyrosinemia Type 1. Succinylacetone is a better marker, but would require different technology for screening. This technology requires different reagents, increased handling of specimens and reagents, and increased staff time. Amount requested from laboratory developmental fund account is $00000, with an anticipated increase in the newborn metabolic screening fee going forward is $000, Dr. Copeland states that with this new technology, we will be able to decrease the amount of re-screening necessary, because we can raise the cut-off. Discussion of validity of test methods – reassuring that test is valid. Motion to recommend that IDPH approve use of developmental funds to add new methodology: Ziese; Second: Degnin/McDowell Vote: Aye 10, Nay 0, Abstain: Copeland, Berberich. Motion carried.

### Agenda item: Proposal for new LIMS for INMSP and MSAFP

**Presenter:** Berberich/Shirazi

**Discussion:**
Current INMSP system is stand alone within the UHL, and was designed in 1996/97. The current MSAFP system is a newer generation LIMS-related database, built in 2000. Discussion of funding amounts that would be the responsibility of the newborn screening and prenatal screening programs compared to the other UHL programs. Project timeline was discussed. Potential for integration with other programs was discussed (OpenMRS as example). Motion to recommend IDPH approve use of developmental funds in the amount of $300,000 from INMSP fund, and $150,000 from MSAFP accounts: Degnin; Second: Waldron. Aye 10 Nay 0 Abstain - Copeland, Berberich. Motion carried.

Berberich – discussion about drafting a policy to allow providers access to INMSP results of infants that are not their primary patient. Piper will request a copy of Minnesota’s policy.

**Agenda item: Recognition of new members**
**Presenter: Piper/Mofle**

Dr. Francis Dominic Degnin, Dr. Sandra Daack-Hirsch, and Dr. Debra Waldron were welcomed. Allison Heffern is a new attorney member.

**Agenda item: FY09 Schedule**
**Presenter: Piper**

**Discussion:**
The schedule for FY 2009 was reviewed.

**Agenda item: Next meeting October 17, 2008**
**Presenter: Piper**

**Discussion:**
Agenda items: October 17, 2008
Review Principles of Ethics; Newborn Metabolic Fee increase/budget; Administrative code update to Chapter 641 IAC 4; review program annual reports

**Action items:**

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<td>Adjourn</td>
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Discussion: Copeland moved, Ziese second Adjourned 3:00 p.m.