CIDAC Meeting

July 18, 2008
1:00 p.m.
Wells Fargo Bank, Grinnell, IA

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

Attendees:
Jerry Wickersham, Iowa Insurance Division; Dr. Sara Copeland, Division of Medical Genetics, INMSP
Medical Director; Dr. Bradley McDowell, Iowa Registry for Congenital and Inherited Disorders; Dr. Roger
Williams, OB/GYN U of I; Nancylee Ziese, Consumer; Dr. Kristi Borowski, Iowa American College of
Obstetricians and Gynecologists, Shelley Ackermann, Dept. of Education; Dr. Lisa Mofle, Family Practice;
Patti Rawson, Social Worker; Stan Berberich, UHL; Dr. Paul Romitti U of I College of Public Health;

Absent:
Senator Amanda Ragan; Representative Beth Wessel Kroeschell; Brian Wilkes; Tiffan Yamen; Blythe
Stanfel; Dr. Deb Schutte, Iowa Nurses Association; Dr. Robert Shaw, Iowa American Academy of
Pediatrics, Christopher Atchison, UHL; Molly Guard, Volunteer Agency March of Dimes Dr. Greg Garvin,
DO;

Others in Attendance: Carol Johnson, UIHC; Marcia Valbracht, UHL; Beth Dowd, UIHC

Quorum present

Minutes

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

Agenda item: Approval of Minutes
Presenter: Lisa Mofle
Discussion:
Motion to approve minutes as amended – Copeland, 2nd Ziese – motion carried.

Action items

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Agenda item: Announcements
Presenter: Members/guests
Discussion:

Johnson - Faculty recruiting. Initially thought two recruits may be coming, but now that is not the case. Back to
square one – this will impact the number of patients we can see. IC clinics are booked through December, regional
clinics almost booked through the same period. Much competition for geneticists. Dr. Borowski has completed her
fellowship in genetics, now is faculty in OB/GYN. Flooding – three days where "nonessential" personnel did not
work. Billing and accounting is about three weeks behind. Berberich – Copeland - The INMSP program continued
without difficulty during the flooding – the courier had to use some back roads to pick up specimens, putting in
additional miles and hours. Courier kept in constant contact with Ankeny lab. Implemented the emergency
call/contact system during the "acute phase" of the flooding. Stan queried the lab database for specimen pick-up
times, and Mercy CR was about a day behind. A Web accessible information system was very beneficial as staff
worked off-site. If necessary, lab personnel from Oakdale could be in Ankeny to work within 2 ½ hours to aid testing.
Piper will draft a letter of appreciation to the courier, signed by IDPH Dir. Newton and Dr. Lisa Mofle.

**Agenda item: I**DPH/CCID/update  
**Presenter:** Kim Piper

**Discussion:**
The federal Genetic Information Non-discrimination Act (GINA) was signed by President Bush in May, and takes effect in July of next year.
Piper is working with colleagues in the chronic disease prevention bureau to establish a relationship between the programs. Will include updates to Web sites, state plan, and common education materials re: chronic disease and genomics.
New grant submitted: INSSP – requesting ~$136,000 to expand the IRCID to include surveillance for confirmed newborn screening cases.
IFPP- project update.
Ethicist and attorney representation on CIDAC – both individuals have declined the position for now. Will contact other attorney and bioethicist from other committees (now defunct) to determine interest.

**Action items**

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<td>Budget Update – Berberich - Examining budget, specifically impact of &quot;loss&quot; of Louisa screening. Had used temporary staff to handle testing load during the past three years. Now still doing the assay testing for LA (which is staff intensive). Looking at staffing requirements, reagent costs, testing methods, etc. with current situation. This may impact the screening fee for next year. Also, courier surcharge has increased 15% due to fuel costs. Through looking at the database, see a trend toward increased turn-around time on the weekends by birthing facilities. Perhaps they haven’t changed their internal procedures, even though the lab has increased their testing capabilities. Pursuing opening access to testing results electronically, instead of paper. Looking at putting results directly into the hospital’s system through an interface. Different per hospital, depending on information systems. Terminology varies as well. Looking at switching to HL7 as standard IT language through project of Public Health Informatics Institute. Dari participates on this PHII project. In the future, this type of process will have a significant impact on the laboratory. Increasing requirements for analysis systems place a burden on the current process, including the recommended screening panel and testing methods used to detect these disorders. (See developmental funds agenda item.) Will see a recommended increase in the screening fee for ’09-’10.</td>
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**Agenda item:** INMSP purpose statement  
**Presenter:** Dr. Copeland

**Discussion:**
The Executive Committee felt that a statement of purpose was needed for the INMSP program to guide programming and decision making.
The final draft of the INMSP purpose statement reads:

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

Final draft will be presented at next meeting for approval.

**Agenda item:** Use of NBS Developmental funds for equipment  
**Presenter:** Berberich

**Discussion:**
Need to consider the addition of a machine to test for recommended disorders to more adequately detect some disorders. Currently using a “home grown” testing kit.

Hemoglobinopathy testing method also being examined, and will be presented.

Berberich will present a proposal at the next October CIDAC meeting regarding using developmental funds to purchase additional machinery needed, and potential fee increase need to sustain testing methodology.

Proposal will include comparison of current testing method and proposed method.

**Agenda item:** Informed Consent for Maternal Serum/Dried Blood Spot specimens

**Presenter:** Romitti

**Discussion:**
IRCID requirements included as one of the centers of excellence for birth defect surveillance, are to collect biological specimens (buccal swabs) from registered children. Now asked by the study to expand the biological sampling process (blood draws, cord blood, NB blood spots, maternal serum, etc.). IRCID would like access to maternal serum samples to review “pre-exposure” markers. These would include identifiers.

Discussion – storage costs? Currently, MS samples discarded within a month. IRB informed consent needed? All women currently sign the same consent form for MSAFP, with the option to opt out allowing storage of their specimen. For the cholesterol study, the identifiers are eventually stripped from the specimen. The IRCID would never strip the identifiers.

Specimen storage policy will be updated to include storage and retention of MS specimens as per administrative rules.

Borowski and Berberich will draft proposal for purchase of equipment for storage on MS samples up through 5 years.

Specific consent forms will need to be used by each research project according to their IRB policy.

**Agenda item:** Recognition of out-going officers

**Presenter:** Piper

The CIDAC Members and others present thanked Roger Williamson, and Jerry Wickersham for their service to the committee as officers this past year.

**Agenda item:** FY09 Schedule

**Presenter:** Piper

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

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

**Presenter** Trout/Piper

**Discussion:**
Agenda items: October 17, 2008
Program annual reports, Review State Plan status, Needs Assessment, Policy/Procedure Update

**Action items:**

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