

Team Meeting

January 18, 2008

1:00 p.m.

Wells Fargo Bank, Grinnell, IA

Meeting called	Christina Trout	Type of	CIDAC
Facilitator:	Kim Piper	Note taker:	Kim Piper
Attendees:	Jerry Wickersham, Iowa Insurance Division; Dr. Sara Copeland, Division of Medical Genetics, INMSP Medical Director; Christina Trout, U of I Clinical Genetics Staff; Dr. Bradley McDowell, Iowa Registry for Congenital and Inherited Disorders; Dr. Roger Williamson, OB/GYN U of I; Molly Guard, Volunteer Agency March of Dimes; Dr. Paul Romitti U of I College of Public Health; Nancy Lee Ziese, Consumer; Dr. Greg Garvin, DO; Dr. Kristi Borowski, Iowa American College of Obstetricians and Gynecologists,		
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, Shelley Ackermann, Dept. of Education; Dr. Lisa Mofle, Family Practice; Stan Berberich, UHL; Christopher Atchison, UHL; Patti Rawson, Social Worker;		
Others in Attendance:	Carol Johnson, UIHC; Kimberley Turner, UIHC; Beth Dowd, UIHC; Leah Jones, UIHC; Laurie Robison, IDPH, CCID		

Quorum present

Minutes

Agenda item:	Introductions	Presenter:	
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Discussion:

Members and guests introduced themselves and the organization they represent.

Agenda item:	Approval of Minutes	Presenter:	Christina Trout
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Discussion: Motion – Wickersham, 2nd Copeland – minutes approved.

Action items	Person responsible	Deadline
✓ Minutes posted to CCID Web site	Piper	4/1/2008

Agenda item:	Announcements	Presenter:	Members/guests
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Discussion:

Christina Trout - The Neuromuscular Program will be indirectly impacted by the hiring of 3 Child Neurologists (Steve Stasheff, Alex Bassuk, Charuta Joshi). The new faculty specializes in neuro-ophthalmology, CNS development and epilepsy. This should be helpful to free NM Program faculty (Dr. Mathews) to see NM patients. There are two internationally-recognized meetings occurring in Iowa City this year, including the Facioscapulohumeral Dystrophy Society and the Congenital Muscular Dystrophy workgroup. Kudos to Iowa.

Agenda item: IDPH/CCID/update **Presenter:** Kim Piper

Discussion:

IDPH budget process – Budget proposals to the Gov were budget neutral (any increases need to be offset by decreases in other programs). Legislature already taking action on various bills – shaken baby, postnatal tissue and fluid banking, newborn hearing screening bills. Now is not the time to ask for increased funding for programs, since they are looking at a flat budget.

2008 Legislative session – it is anticipated that there will be no genetic-specific programs addressed in the next session, as there will be a focus on a flat budget and it being an election year. The possible exception would be action on the Postnatal Tissue and Fluid Banking Task Force recommendations.

Action items	Person responsible	Deadline
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Agenda item: Hemophilia Advisory Committee Annual **Presenter:** Laurie Robison

Discussion:

HAC Annual Report was distributed.

Members appointed over the summer, and a report was written and provided to the legislature re: concerns and issues of persons with hemophilia, clotting and bleeding disorders. Next steps are to formalize the committee, and develop education and awareness for local communication. This committee will continue as a stand-alone committee for the foreseeable future.

Agenda item: Program Updates **Presenter:** Program Staff

Discussion:

Christina Trout – new faculty mentioned previously. At last meeting it was reported that they are not diagnosing DMD at rates expected, but since then, are diagnosing more at expected rates.

Sara Copeland- NBS – Arlena Pugliese has resigned effective Feb 4th, but will be contracted for 20% time for ongoing support. Kimberley Turner will assume Arlena's responsibilities. Will probably increase the SW % to FT.

Carol Johnson– still recruiting for geneticists. Second visit by recruit this week. Two more recruits in the pipeline. Would like two more geneticists, but may get only one.

There are changes occurring in both the administrative and financial structure at UIHC as well as in the Carver College of Medicine.

Roger – Integrated screening program provides a remarkably reduced false positive rate. Still dealing with patent issues with the patent coordinator at Perkin-Elmer. Have signed agreement with Nick Wald. This will be the only program in the country combining integrated screening with repeat measures screening.

Agenda item: Genetics Program Advocacy **Presenter:** Molly Guard/Carol Johnson

Discussion:

MoD Lobby Day Feb 7th. In the rotunda. Will remove genetic program funding advocacy from priority list in deference to flat budget, but will continue to promote awareness of programs. MoD will work with other programs to support prevention of smoking in public places via local ordinances. Presumptive eligibility for children. Garvin – BOH statement was for no-smoking (broad) but not taking a stance on how this is accomplished (i.e. preemption).

MoD will provide a conference call prior to lobby day to assist in the lobby day education.

Agenda item: Fiscal Plan Preview **Presenter:** Kim Piper for Stan Berberich

Discussion:

Dr. Berberich was unable to attend due to family illness. There are no increases proposed in the newborn screening or maternal screening budgets for next fiscal year. For FY10, potential additional tests to screening panes may require increase (CMV screening, integrated maternal screening).

Agenda item: Nomination Subcommittee **Presenter:** Christina Trout

No members have terms expiring in July, however there are still two vacant positions (Ethicist and Attorney), and will need to elect new Chair and Vice Chair in April to assume positions in July. Sara Copeland has suggestion for an ethicist, and Nancy Ziese has a recommendation for an attorney. Both of these individuals will be contacted by Kim Piper to determine their interest in serving.

Action items	Person responsible	Deadline
✓ Contact potential new members.	Kim Piper	April 1, 2008

Agenda item: Proposal to screen for cholesterol as a marker for increased risk to deliver prematurely **Presenter:** Roger Williamson/Kristine Borowski

Discussion:

Dr. Borowski made a brief presentation – some recently published results from a small study indicate that moms with low or high cholesterol levels in the 2nd trimester have an increased risk for preterm delivery. Proposing a prospective screen that looks at cholesterol samples from 1st and 2nd trimester. Members discussed format and funding of such a proposal, including partnering with the Registry for surveillance capacity, or applying for March of Dimes grant funds.

Action items:	Person Responsible	Deadline
Formalize proposal for presentation at next meeting	Drs. Borowski & Williamson	April 18, 2008

Agenda item: IRCID 25th Anniversary **Presenter:** Paul Romitti

Discussion: The Registry will be celebrating data collection activities for 25 years this year (beginning in 1983). However, the Registry wasn't officially established by Code until 1986, making 2011 the 25th anniversary. Christina trout made a motion to wait to recognize the 25th anniversary until 2011. Motion 2nd by Roger Williamson. Motion carried.

Brad McDowell – the Registry's annual report will be posted on the IRCID Web site at <http://www.public-health.uiowa.edu/ircid/> rather than distributed in hard copy this year.

Action items:	Person Responsible	Deadline
Post annual report to IRCID Web site.	Paul Romitti/Brad McDowell	April 1, 2008

Agenda item: Schedule FY 2008 **Presenter:** Christina Trout

Discussion: The schedule for FY2008 was reviewed, and the schedule for FY2009 planned. Meeting dates for 2009 are July 18th, October 17th in 2008, and January 16th, April 17th in 2009. Next meeting is April 18, 2008 in Grinnell.

Action items:	Person Responsible	Deadline
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Agenda item: Adjourn **Presenter:** Christina Trout

Discussion: Meeting adjourned 3:15 p.m.