

Team Meeting

October 26, 2007

1:00 p.m.

Wells Fargo Bank, Grinnell, IA

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| Meeting called | Christina Trout | 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; Christina Trout, U of I Clinical Genetics Staff; Stan Berberich, UHL; Dr. Bradley McDowell, Iowa Registry for Congenital and Inherited Disorders; Dr. Roger Williamson, OB/GYN U of I; Patti Rawson, Social Worker; Dr. Lisa Mofle, Family Practice; Christopher Atchison, UHL; Molly Guard, Volunteer Agency March of Dimes; | | |
| Absent: | Senator Amanda Ragan; Representative Beth Wessel Kroeschell; Brian Wilkes; Dr. Paul Romitti; Tiffan Yamen; Blythe Stanfel; Shelley Ackermann, Dept. of Education; Nancy Lee Ziese, Consumer; Dr. Greg Garvin, DO; Dr. Deb Schutte, Iowa Nurses Association; Dr. Kristi Borowski, Iowa American College of Obstetricians and Gynecologists, Dr. Robert Shaw, Iowa American Academy of Pediatrics, | | |
| Others in Attendance: | Carol Johnson, UIHC; Arlena Pugliese, UIHC; Judy Miller, UIHC; Pam DeBoer, UIHC; Leah Jones, UIHC; Laurie Robison, IDPH, CCID | | |

Note: attendance does not meet requirements for a quorum

Minutes

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| Agenda item: | Introductions | Presenter: | |
| Discussion: | Members and guests introduced themselves and the organization they represent. | | |
| Agenda item: | Approval of Minutes | Presenter: | Christina Trout |
| Discussion: | Approval of minutes was tabled due to lack of a quorum. | | |
| Action items | Person responsible | Deadline | |
| ✓ Minutes posted to CCID Web site | Piper | 1/18/2008 | |
| Agenda item: | Announcements | Presenter: | Members/guests |
| Discussion: | Christina Trout – One of the neurologists who initially decided to come to the U of I has decided not to come. Recruitment efforts are ongoing. | | |

Agenda item: IDPH/CCID/update

Presenter: Kim Piper

Discussion:

IDPH budget process – The Department has drafted budget offers for public health services to present to the Governor’s office for his consideration. The Governor has requested no increase in budget proposal amounts from last year.

HRSA MCHB has awarded the Center for Congenital and Inherited Disorders funding to determine newborn screening program participant’s perception of the screening programs, and to increase participation in the planning, implementation, and evaluation of newborn screening programs in Iowa. The Iowa Family Participation Project (IFPP) grant awards IDPH \$100,000 for each of the next three years. An additional \$30,000 was awarded for year one to include hearing screening participants. There has been difficulty establishing a relationship with the Native American Indian representative at the Meskwaki Settlement in Tama. Chris Atchison recommended contacting Joe Coulter for assistance, as he has experience working with this population.

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: Program Updates

Presenter: Program Coordinators

Discussion:

Program Annual Reports were distributed.

Carol Johnson presented and answered questions regarding the Metabolic Low Protein Food Program, the Metabolic Formula Program, and the Regional Genetics Consultation Services program (in Cathy Evers’ absence).

Christina Trout reviewed the Neuromuscular and Related Disorders report and answered questions.

Dr. Roger Williamson presented the Iowa Expanded MSAFP Screening report and responded to questions

Dr. Brad McDowell – the IRCID will not be providing an annual report in the usual format this year, but will provide information via the Web site.

Agenda item: Integrated Screening Proposal/use of developmental funds

Presenter: Drs. Roger Williamson and Stan Berberich

Discussion:

Dr. Williamson presented a research proposal to establish a statewide integrated screening program using markers from the first and second trimesters. The proposal, an article explaining integrated screening, and a sample provider letter were provided for review. A request was made to use developmental funds for the building of the program and implementation of the courier service for specimen collection. Discussion was held. Dr. Copeland noted that education of providers should be a priority, and every provider should be provided education on integrated screening for the program to be successful. Members were reassured that using the courier service to transport integrated screening specimens would not delay the transport of NBS blood spot specimens to the UHL. After the initial phase, the screening fee will be increased to cover the costs of the courier service and integrated screening program.

A vote was not held, as there was not a quorum present.

| Action items | Person responsible | Deadline |
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✓ Schedule and post information for a conference call to vote on approval of the proposal and use of developmental funds.

Piper/Williamson/Berberich ASAP

Agenda item: Stem Cell/Postnatal Tissue and Fluids Banking

Presenter: Roger Williamson/Kim Piper

Discussion:

HF910 – Establishes a task force on postnatal tissue and fluid banking. Harkin has introduced legislation again to allow federal funding that supports stem cell research. The Task Force has met, and will be finalizing a report of recommendations to present to the legislature. The recommendations include establishing a statewide umbilical cord blood banking network, to be administered by the University of Iowa.

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| Action item: | Person Responsible | Deadline |
| Post Task Force report of recommendation to Web site. | Kim Piper | Upon completion |

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| Agenda item: One Millionth Baby Screened | Presenter: | Kim Piper |
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Discussion:

November 20th is the scheduled date for the recognition. Discussion was held as to the format of the recognition, and it was suggested that rather than choose a baby to represent the one-millionth baby screened, the recognition should focus on the accomplishments of the program. Kim Piper will work with Pat Blake and the communications staff at IDPH to develop a recognition program.

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| Action items | Person responsible | Deadline |
| Establish a program for the recognition of Iowa screening its one-millionth baby. | Piper et al | 11/20/2007 |

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| Agenda item: Schedule FY2008 | Presenter: | Christina Trout |
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| Action items | Person responsible | Deadline |
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| Agenda item: LEP Plan | Presenter: | Kim Piper |
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Discussion:

Kim Piper will be drafting a plan for assuring all genetic services are accessible to persons with Limited English Proficiency (LEP). The draft plan will be submitted for review and approval by the committee.

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| Action items: | Person Responsible | Deadline |
| Develop draft LEP plan for genetic services | Kim Piper | ASAP |

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| Agenda item: Schedule FY 2008 | Presenter | Christina Trout |
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Discussion: The schedule for FY2008 was reviewed. The next meeting is January 18, 2008, same location.

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| Action items: | Person Responsible | Deadline |
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| Agenda item: Adjourn | Presenter: | Christina Trout |
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Discussion: Meeting adjourned 3:05 p.m.