Minutes

Agenda item: Introductions
Discussion: Members and guests introduced themselves and the organization they represent. Christopher Atchison was introduced as the new Director of the UHL.

Agenda item: Approval of Minutes
Discussion: Amendments – Patti Rawson name misspelled, addition of Cathy Evers as attendee, changes to presentation on MSAFP Integrated Screening presentation by Dr. Williamson. Wickersham – moved to approve minutes as amended; Copeland second. Motion carried.

Action items
- ✓ Minutes posted to CCID Web site
  Person responsible: Piper
  Deadline: 9/30/2007

Agenda item: Announcements
Discussion: Christina Trout - Have hired two new pediatric neurologists - one is already working. Have two more coming next year.
Carol Johnson – Sharon McMillan passed away the beginning of May from lung cancer. Will be recruiting for her position. Faculty recruiting – down two geneticists at this point in time. Scheduling clinic visits into November now. Carol’s responsibilities will be reorganized; with the addition of the new Project Asst to the Division of Medical Genetics (Lisa Neff-Letts), Carol Johnson will be taking on some administrative duties for the Division of Child Neurology, including the Neuromuscular Program. At the APHL annual newborn screening meeting in April, three poster presentations were made by the Iowa attendees – two posters received recognition.
Agenda item: Introduction & Welcome New Members

Discussion:
Dr. Robert Shaw is the new AAP representative. Dr. Kristi Borowski is the new ACOG representative. Still recruiting attorney and bioethics representatives.

Action items

Agenda item: IDPH/CCID/update

Discussion:
IDPH budget process – The Department is drafting 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.
Laurie Robison is recruiting members for the legislatively mandated hemophilia advisory committee. The committee will meet for a year, then consideration will be made regarding “rolling” this committee into the CIDAC.
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.

Action items

Agenda item: INMSP Fiscal Update

Discussion:
No new fee increase. Sara Copeland - Would like to increase the dietitian’s percent of effort to 100% (currently 50%). Nancylee moves to approve having 50% of the dietitian’s time paid from formula funds. (The rest of her time is paid from the INMSP diet.) Seconded by Mofle. Copeland abstained. Motion carried.

Nancylee Ziese asked about the status of the courier program – successes? Program very successful. There have been a couple of MCADD babies that have died, but that was due to the specimen’s being collected at the later end of the required collection timeframe, not a delay in transportation or testing of sample.
The MoD recognized the INMSP program via a press conference on July 13th. This recognition of the INMSP was appreciated.

Conclusions: Motion carried to increase dietitian’s percent of effort to 50% formula funds and 50% INMSP dietary appropriation.

Agenda item: Program Updates

Discussion:
Beth Dowd – CF in 2007 86 positives screens with 8 diagnoses. On track with what was expected. In the first screen was changed from the top 5% getting mutations run, to an IRT above 65 (about 3%) will get mutations run. Carrier screening is now limited to parents, and not other family members.
Sara Copeland– INMSP Executive committee – trying to develop INMSP as a program, rather than being told what the program will do (similar to recent mandates in IL and NYC where new tests are mandated). There are three
subcommittees (education, financial, and research), that address specifics.
Carol Johnson– RGCS – shifting of personnel, Jenny Marcy has resigned her position with the RGCS program to become the new genetic counselor for the NBS Program. Karin Panzer has been recruited to fill Jenny’s position in RGCS.

Metabolic formula/medical foods – able to shift unused medical food balance to provide metabolic formula for those participants still needing formula.
Brad McDowell– the IRCID has finished collecting data for the pilot phase of the stillbirth project, and has started some analyses to determine what they are able to find in the medical records. This will help revise the abstract and prepare for prospective monitoring across the state.
Roger Williamson – integrated screening targeted implementation date in the fall. Have been working on planning the program implementation. Some agencies may need a few months lead time to develop the capacity to provide integrated screening. We will provide the service free-of-charge as a pilot to determine true costs. A packet containing a letter from the IDPH, patient education packets, informational materials, etc. will be sent to obstetric health care providers. Will have a program implementation report at the October meeting. Stan Berberich– meeting with the courier to determine if the courier be advantageous for this program.

Stan Berberich– INMSP lab. LA was originally planning to take their program back in July, now looks like they will be taking it back pending CLIA approval, possibly in October. The courier program is going very well, however still need to monitor hospital processes to guarantee the fastest turn-around time available (once LA takes their program back, staff will have more time for the hospital-based reviews and education).

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 U of I currently banks umbilical cord blood for research.

Agenda item: Use of Residual Maternal Serum specimens                Presenter: Dr. Janet Fairley
Discussion:
Dr. Janet Fairley from the University of Iowa Department of Dermatology presented a research proposal to use residual maternal serum samples to study autoimmune diseases of pregnancy – Interest is in how and why these antibodies develop. Specifically, pemphigoid gestationis (PG). PG is characterized by the development of Autoantibodies against the Cutaneous autoantigen BP180. These antibodies cause a blistering disorder. A fair number of normal pregnancies also have these antibodies. The proposal requests permission to collect anonymized, residual serum from AFP testing. They will compare the incidence in pregnant women to non-pregnant controls that will be collected from their clinic population. They would like to have the specimens to determine the incidence of these cutaneous antibodies. They would then determine if they need to do a longer-term study to see if these antibodies would be a marker for high-risk pregnancies A motion to approve the provision of residual maternal serum samples was made by– Copeland, Motion seconded by Mofle. Discussion: - statement regarding the storage and disposition of residual serum samples must be in the MSAFP brochure and in administrative rules. This committee’s approval will allow the Dermatology program to receive IRB approval to proceed with the project once the administrative rules are approved and adopted/filled. Jerry – move to amend motion to state proposal approved pending adoption and filing of administrative rules. Amended motion: Request from U of I Dermatology Department to use de-identified MSAFP residuals approved, pending publication of information regarding the storage and disposition of residual MSAFP samples in the Iowa Administrative Code and the informational brochure provided to pregnant women. The CIDAC will also consider expanding existing blood spot retention policy to include MSAFP (and other specimens). Handouts include current residual blood spot use policy, proposal from U of I dermatology department. Discussion re: informed consent, implied consent, IRB, etc. considering de-identified samples will be used. Motion to approve amended motion by Copeland, 2nd - Mofle. Motion passed. Kim Piper will meet with the AAG and follow-up on amendment to brochure.

Action items Person responsible Deadline
✔ Discuss adding other specimens to blood spot retention & use policy with AAG, amend administrative rules and AFP brochure  Piper/Williamson  11/30/2007

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**Agenda item:** One Millionth Baby Screened  
**Presenter:** Kim Piper

**Discussion:**  
October is anticipated date for the one-millionth Iowa baby to receive INMS testing. Rebecca Gernes is an intern working with Kim Piper, and she will be responsible for coordinating the one-millionth baby screened recognition with Judy Miller, Blythe Stanfel, Tiffan Yamen, and Marcia Valbracht.

**Conclusions:**

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**Agenda item:** Schedule FY2008  
**Presenter:** Kim Piper

Roger Williamson – Request to move next meeting date, so that he may present the status of the integrated screening project. Wickersham moved that the meeting be held on October 26, 2007. Copeland second. Motion carried. Next meeting Friday, October 26th. Wells Fargo Bank Building.

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**Agenda item:** Adjourn  
**Presenter:** Christina Trout

**Discussion:** Meeting adjourned 2:55 p.m.