Minutes

Agenda item: Introductions
Discussion:
Members and guests introduced themselves and the organization they represent. Kyna Byerly was introduced as a visitor/guest from the Heartland Regional Genetics and Newborn Screening Collaborative, of which Iowa is a member. Kyna is observing the meeting today.

Agenda item: Approval of Minutes
Discussion:
Wickersham - Motion to approve minutes from October 19, 2006 as written. 2nd Trout. Vote – motion carried.

Action items
- Minutes posted to CCID Web site
  Person responsible: Piper

Agenda item: Announcements
Discussion:
Carol Johnson - The U of I Dept. of Pediatrics Division of Medical Genetics received approval from the accrediting agency (ACGME) for a Clinical Medical Genetics Residency Program (fellowship) retroactive to 7/1/06.
Beth Dowd – Sharon McMillan, nurse with the short-term follow-up program, has been hospitalized with complications from lung cancer. She is now in palliative care. A card to be presented to Sharon was circulated for signatures.
Agenda item: IDPH/CCID/Legislative update

Presenter: Kim Piper

Discussion:

Piper and Kyna Byerly presented information about the Heartland Regional Genetics and Newborn Screening Collaborative. Please visit the Heartland Web site: http://heartland.ouhsc.edu for useful information and for the date and call-in information for the next Heartland Executive Committee conference call on May 3rd. All are invited to call in.

Governor Culver still has not named director for the IDPH. Mary Jones is the Interim Director.

Legislative update: SF548 Hemophilia Advisory Committee – signed by governor. Establishes a hemophilia advisory committee effective appropriation. HF910 – Postnatal tissue and fluid banking – passed House – to Senate HF738 – Mandated insurance coverage for HPV vaccine, enteral formula, and hearing aids – placed on unfinished business calendar

Action items

- Participate in Heartland Conference Call if desired

Person responsible: Members/guests

Deadline: May 3rd

Agenda item: INMSP Fiscal Plan

Presenter: Stan Berberich/Carol Johnson

Discussion:

UHL fiscal plan presented by Berberich – Plan for an additional MS/MS machine, and punch. Increase in salaries, and staff time. This can be offset by the revenue received from LA testing, and the upcoming SD testing. Does not anticipate needing to raise the screening fee for the next couple of years.

UIHC fiscal plan presented by Johnson – salary increase – offset by reallocation of % of effort for medical consultants. Does not see need to increase screening fee this fiscal year.

Conclusions:

Motion to approve acceptance of the INMSP fiscal plan by Ziese. 2nd by Garvin. Vote – motion carried.

Agenda item: Program Updates

Presenter: Program Coordinators

Discussion:

Dowd - CF – 2006 - 181 babies identified needing further testing; 22 diagnosed CF, 149 carrier; 15 parents tested. 2007- 47 identified; 7 diagnosed CF. Assisting Michigan in setting up their program. UHL assumed screening x 2 weeks for MN while they worked on issues with their testing.

Copeland - Metabolic – Courier program has assisted with early ID of a child with ASA – a urea cycle defect. Berberich reported that we could expect to screen the 1 millionth baby sometime later this summer/early fall. On behalf of the CIDAC Dr. Williamson asks the 1 millionth baby committee to reconvene. Stanfel will lead the group in planning for this recognition.

Trout – Neuromuscular program – very busy! Two neurologists coming in July – very little clinical time, however, so minimal support for Dr. Matthews in clinics. Still recruiting – universal shortage of peds neurologists. Not really diagnosing as many Duchenne cases as expected– only two per parent initiative, usually 5/yr. Other states also experiencing this. Increase in spinal muscular atrophy cases (6 so far this year, usually 6/yr).

Evers - RGCS – loss of two medical geneticists (Kanis and Al-shanti). Counselor moving to metabolic NBS program so will be recruiting a new counselor.

McDowell – Iowa Registry for Congenital and Inherited Disorders – Stillbirth surveillance ongoing. Discussion re: the “Delivering Moms’ work” – a group of women who have had stillborn children that have started grassroots efforts to raise awareness about stillbirth and to promote “kick counts” for pregnant women to promote healthy pregnancies and fetal monitoring.

Williamson - MSAFP (Handout provided)– 1in 52 women with elevated levels had a child with a NTD. 1 in 11 patients had a fetus with a defined fetal anomaly. Seeing a lot of gastroschisis. 3.3% of all women screened were + for chromosomal abnormalities (mostly Down syndrome). Of 89 women, 1 had Trisomy 18, and one with other multiple anomalies. Smith Lemli Opitz Syndrome (SLOS) screen beneficial for screening multiple disorders, and recommend that it be continued. Have been able to do integrated screening for 3 years now. Decreases the number false +, avoiding amniocentesis. Through better US technology, doing fewer amniocenteses, but still maintain the expected rate of Down syndrome diagnosis. Women want a good test, no false positives, as early as possible without invasive procedures. Integrated screening meets all of these needs. Should have legal approval to use the patented test (controls to establish medians/means and software) to begin integrated screening by July. Handout provided.
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: New Tests/Procedures/Policies

Presenter: Roger Williamson/Kim Piper

Discussion:

Request from U of I Dermatology Department to use de-identified MSAFP residuals. 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 amend pamphlet, consult with Assistant Attorney General (AAG), and expand existing policy – by Copeland, 2nd - Mofle. Motion passed. Kim Piper will meet with the AAG and follow-up on amendment to brochure.

Other tests on horizon explained by Dr. Copeland. MD testing is the Losartin trials work like hope (CK), MD, Fragile X, CMV testing. The CIDAC recommended that CMV testing be considered as part of the newborn hearing screen, and under the purveyance of the state newborn hearing screening program.

Action items

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Agenda item: Nominations/Election of Officers

Presenter: Roger Williamson

Discussion:

Dr. Williamson solicited nominations for committee chair and vice chair. Christina Trout nominated for chair by Ziese, 2nd by Williamson. Vote – Trout incoming chair of CIDAC. Wickersham nominated for vice chair by Trout. 2nd by Copeland. Vote – Wickersham incoming vice chair.

Kristi Borowski nominated to represent the ACOG on the committee.

Conclusions:

Incoming Chair – Christina Trout; incoming Vice Chair – Jerry Wickersham

Action items

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Agenda item: Schedule FY2008

Presenter: Kim Piper

Next meeting Friday, July 20th. Wells Fargo Bank Building.

Action items

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Agenda item: Adjourn

Discussion: Meeting adjourned 3:25 p.m.