CALL TO ORDER:
Deb Schutte called the meeting to order at 1:00 p.m. and presided over the meeting. Introductions were made.

MEMBERS PRESENT:
Debra Schutte, Shelley Ackermann, Peggy Stokes, Christina Trout, Nancylee Ziese, Val Sheffield, Stanton Berberich for Mary Gilchrist, Roger Williamson, Molly Guard, Amanda Ragan, and Gregory Garvin.

MEMBERS ABSENT:
James Matsuda, Neil Mandsager, Paul Romitti, Celest Johnson, Pat Murphy, Jerry Wickersham, Jeffrey Lobas, Linda Brown, Jolene Johnson, and Michelle Hall.

OTHERS ATTENDEES:
Judy Miller, Katherine Baker-Lange, Carol Johnson, Joy Haidle, Karen Brewer, Pam DeBoer, Catherine Evers, Julie McMahon, Tonya Diehn, Dawn Mouw, Tammy O'Hollearen, Lori Graham, and Sherry Smith.

NEW MEMBERS:
Debra welcomed Shelley Ackermann to the committee. Shelley is the Department of Education representative. Tonya announced that Dr. Robert A. Lee would be joining the committee. He will be representing the Iowa Academy of Family Physicians.

APPROVAL OF MINUTES:
Deb noted that the minutes for the January 17, 2003 and the April 18 2003 minutes had been provided to all and asked if there were any changes. No changes.

Motion to approve the January minutes was made by Peggy Stokes. Seconded by Val Sheffield and Christina Trout.

Motion to approve the April minutes was made by Nancylee Ziese. Seconded by Val Sheffield.

ANNOUNCEMENTS:
Molly Guard announced the MOD Prematurity conferences:
July 23, 2003; 11:00 a.m. Preventable Causes of Prematurity. The conference will be presented by Dr. LeRoy Yates of the Genesis Health Group and will discuss the issue of pre-term birth, including prevention strategies. The conference will be broadcast to sites in Dubuque, Bettendorf, Sioux City, Des Moines, and Iowa City.

- September 18 –Ethics and Technology for Prematurity in the States and Abroad The conference will be presented by Dr Edward Bell, University of Iowa. The conference will be broadcast to sites in Mason City, Des Moines, Iowa City, Dubuque, Sioux City, Davenport and Council Bluffs. Bring a brown bag lunch
- November 20 –Parent/Physician Communication in the NICU The conference will be broadcast to sites in Mason City, Des Moines, Iowa City, Cedar Rapids, Council Bluffs, Sioux City, Dubuque, and Davenport.
Molly mentioned that the conferences are free for the attendees who do not wish to use the conferences for continuing education credit. Members of the audience wishing to use the conferences toward continuing education units are required to pay a fee.

I. COORDINATOR REPORT

Tonya Diehn

Notification project for the Birth Defects Registry is moving forward. Letters started being mailed to families approximately three weeks ago.

The Board of Health approved the addition of the expanded panel of tandem mass spectrometry detectable disorders on Wednesday, July 8. Routine reporting of the disorders will begin on August 1. The newborn screening fee will be $56.00. The Birth Defects Advisory Committee recommended the $10.00 fee increase at the April meeting. They also recommended $5.00 be used to support clinical and follow-up needs and that Iowa Department of Public Health and University of Iowa, Division of Genetics determine how the monies would be used. The amount of $1.74 per specimen will be used to hire a nurse practitioner to assist with clinical responsibilities and education services. The need for this position will be reviewed annually. The amount of $3.26 per specimen will be placed in a separate fund for the hiring of a biochemical geneticist.

The Birth Defects Institute Administrative Rules have been opened to add the additional disorders to the newborn metabolic screening panel as well as to add language to permit muscular dystrophy surveillance and long term follow-up of individuals identified by newborn metabolic screening. Some definitions have been added and clarifications made. The notice of intended action was provided to the committee members electronically. If anyone has comments or changes, please provide them to Dawn Mouw. The public hearing is scheduled for August 26 from 11am to noon. The sites are Des Moines, Davenport and Tiffin.

II. IDPH UPDATE

Julie McMahon

Julie reported there would be no cuts to contractors for the FY04 IDPH budget; however, the budget is not final. The department is putting together their legislative agenda for the upcoming session. If anyone has any policy ideas, they should provide them to Tonya.

Julie discussed that all contracts will now have performance measures, payment plans, and incentives and disincentives. These changes are in response to the Accountable Government Act. Within IDPH, a performance plan has been developed for every bureau and program.

Julie and Tom Newton, Director, Division of Environmental Health have been making transformation visits to communities across the state. The purpose of the meetings is for the department to become better partners with communities and local departments of public health. In September and October, Mary Hansen and executive team will make 6 visits.

Christina asked why do they need to indicate early ACCESS referrals in their annual reports. It's a very manual process, no computer. The Neuromuscular Program also can’t determine if Early ACCESS referred the family because the family’s doctor must make the referral. Early ACCESS makes recommendations. Shelley stated that
more exploration should be made regarding the subject.

III. METABOLIC FORMULA PROGRAM REPORT Carol Johnson
Carol provided the annual report for the Metabolic Formula Program (MFP). Copies were distributed to the attendees.

- The MFP has been in place for quite some time, but this is the first formal report that has been written. She was not able to find when MFP originated.
- Overview and accomplishments: MFP was placed under the direction of the Department of Pediatrics, Division of Medical Genetics in August 2001. In collaboration with the Center for Genetics, the BDAC, and the State Hygienic Laboratory, they have been able to better serve the citizens of Iowa.
- $3 addition to Newborn Screening Fee: In November 2003, the $3 increase was approved. The increase was necessary in order to save the MFP because many bills go unpaid causing financial hardship to the program (sliding fee scale, non payment from insurance, Amish, etc). An amendment to the Birth Defects Institute Administrative Rules established the metabolic formula fund. The fund is to be used as a payer of last resort.
- The Amish families do not obtain social security numbers, pay income tax and do not request government incentive. They are eligible for WIC or Medicaid but do not request the assistance. The University of Iowa gives the Old Order Amish Churches of Iowa participants a 15% discount if they pay their medical bill for clinical and hospital visit costs in full within 90 days.
- August 2001: Blue Cross/ Blue Shield of Iowa agreed to pay for formula.

Exception to the Metabolic Provision Policy: Old Order Amish Churches of Iowa successfully petitioned the State of Iowa to waive 641 IAC 4.3(8)"d" on February 18, 2003. The Amish Church will pay 2/3 of the cost of formula for their families. The metabolic formula fund will be used to pay 1/3 of the cost of the formula.

- Protocol Updates: The MFP application was revised for FY03 and updated for FY04 to make it clear to the applicant but yet obtain more information for program staff. A new application form was created for the Amish for FY04.
- The MFP has been through many changes since FY01; including the change of site, change in personnel, procedures (ordering 3 months worth of formula at a time, billing procedures), etc.
- Accounting Systems: Until the end of FY03, an antiquated program called PC File was used to administer the billing portion of the MFP. PC File did every function in isolation, making it impossible to view the program as a whole. In March 2003, U of I Hospitals and Clinics implemented a new billing/scheduling program called IDX. The IDX system has not gone smoothly. Therefore, they decided to use an Excel program for the MFP and not move the program over to IDX for at least another year. After using the Excel program, it was decided that it was a more functional tool to use in the future for MFP. Improvements in the MFP have made tracking of records and deposits less complicated.

There was discussion about the difference between last year and this year's deficit and if the metabolic formula fee covered the needs of the program.

IV. RETINOBLASTOMA: Lori Graham
Tonya introduced Lori Graham. Last legislative session a bill was introduced to add
Retinoblastoma to the newborn metabolic screening panel. The bill was drafted in response to Lori’s effort to have children screened for Retinoblastoma at their well baby checks. Lori knows that Retinoblastoma can’t be detected through the laboratory tests of a newborn screening program. It is detected through clinical evaluation. She is here to share her story and her interest in proposing a new bill. Lori provided the attendees with the brochure she developed, entitled “What is Retinoblastoma”.

Lori’s daughter Sena was diagnosed with cancer of the eye (Retinoblastoma) at four months of age. Since the infant had cancer in both eyes, it was determined that she was born with the disease. Through her own research and the consultation of an opthalmologist, she learned that if the disease had been detected shortly after birth or sooner, the right eye may have been saved. One of the symptoms of the disease is that instead of having the "red eye" effect from flash of a camera, the photo will show a "white eye" effect. Other symptoms the child may have are watery eyes and sensitivity to light. If an infant is diagnosed after 4 months of age, he/she is more likely to lose the sight in the affected eye. Lori's daughter has a 90% likelihood of having a cataract in the affected eye due to the radiation treatment she received. Lori suggests that an infant be tested with a dilated eye exam at 2 weeks old. Retinoblastoma can be hereditary or sporadic. Joy Haidle mentioned that an unaffected parent can pass the Retinoblastoma gene on to his/her children. If a child is born with the disease in both eyes, it is more likely the disease was received from the gene of a parent.

Lori is working with Representative Linda Upmeyer on new legislation for Retinoblastoma screening. Lori would like health care providers to perform a dilated eye exam at the 2-6 week well-baby check. Lori is focusing on detection of bilateral cases. Joy recommended that a pediatric ophthalmologist be involved in the drafting of the bill.

The attendees asked many questions and provided Lori with feedback and potential resources. Dr. Sheffield complimented Lori on her brochure, he felt it was very well done.

Dr. Sheffield mentioned that the U of I has a special camera for photographing infants to aid in the detection of the disease. He also mentioned since the disease is not necessarily genetic, early screening will not rule out all cases. Some children with Retinoblastoma will not have detectable tumors as newborns. Tonya asked Lori if she thought the testing should occur at 2-6 weeks or 6-8 weeks after birth. Lori suggested the infant be tested at 2-6 weeks after birth. Joy stated that if the test is completed too soon, that some infants with the disease would go undetected, especially if they did not receive the disease genetically. She feels the exam should be completed at later time after birth because the disease is only detected when the infant is older than 2-6 weeks. Lori then mentioned that the children aren't diagnosed earlier because they are not tested earlier. If they were tested earlier, the disease would be detected at a younger age. Lori mentioned that she has received consultation from a doctor in California. Lori indicated that there is a video available to train health care providers on how to perform dilated eye exams. Dr. Garvin recommended that primary physicians be surveyed to see how many perform a dilated eye exam and then distribute video. Contact information would be available through the Iowa Medical Society, American Academy of Pediatrics, and the Academy of Family Physicians. Suggested resources for funding video distribution were a March of Dimes grant and/or the Lion’s club.
Dr. Garvin mentioned he agreed with early detection, but it may be difficult for the bill to pass in legislature since the American Academy of Pediatrics has guidelines on dilating the eyes of infants. He also expressed concerns in passing a mandate with the state's current budget constraints. California has passed the bill for early detection and coordinating access to services. The state of Florida is also working on a bill. Katie Baker-Lange discussed that congenital cataracts can also be detected by a dilated eye exam. Perhaps expanding the language of the Iowa bill to include childhood eye disorders such as cataracts and glaucoma would increase its chances.

Dr. Garvin and Dr. Sheffield gave her sources to search for certain doctors that have more experience and knowledge with eye diseases and may show support for the bill to the legislature.

Tammy O'Hollearn suggested that she not exclude family practice doctors from her efforts. Family practice doctors provide care to many children in Iowa.

V. BIRTH DEFECTS INSTITUTE NAME CHANGE    Group Discussion
It has been noted that interested parties feel that the title of the BDAC may be inappropriate or offensive to the families of children born with birth defects. The group was provided with a list of suggested titles for the committee:

- Congenital & Inherited Disorders Center/Institute: The name infers at birth and along life. The group suggested a better title might be "Center for Inherited Conditions. They also suggested "Center for Congenital and Inherited Conditions (Genetic). However, it was noted by that the term "condition" is too general. Social workers and healthcare workers tend to overlook the term "condition" because it covers a broad area and is somewhat general or vague. The term disorder may be more appropriate because it will not be overlooked as often as the term "conditions" may be.
- Iowa Genetics & Health Institute: The group didn't feel that this term was appropriate since it used the term "Institute".
- Center for Genetics and Birth Defects: Someone suggested that this term maybe confused with the Center for Genetics; however, someone did suggest that Center for Genetics and Congenital Conditions may be more appropriate.

Discussion was limited and consensus could not be reached. Shelley suggested the group think about the purpose of the programs of the Birth Defects Institute and capture it in the title. Greg Garvin made a motion to table the item until October. A second motion was made by Shelley Ackermann to reevaluate and redefine the purpose of Birth Defects Institute and reopen the code. Greg Garvin withdrew his motion. Shelley’s motion was restated and seconded by Val Sheffield and Nancylee Ziese. Motion was approved unanimously.

Tonya asked that a subcommittee be established to evaluate the code and purpose of the Birth Defects Institute. Debra, Shelley, Nancylee, Pam and Stan volunteered for the subcommittee. They will report back to the full committee in October.

VI. CYSTIC FIBROSIS SCREENING PROGRAM REPORT Roger Williamson
Roger provided the group with a handout containing the following data.

Pilot Program (July 2002-January 14, 2003): The program received 190 paired
samples:
a) Ethnicity:  Samples were received from 178 European Caucasians; 1 Ashkenazi Jewish; 5 Hispanic Americans; 3 African Americans; 3 Asian Americans.
b) Carriers Detected:  5 carriers were detected among initial samples; 1 carrier detected among partner samples; 1 carrier already known, partner was screened by the program.
c) Providers from UIHC:  FDT/Genetics 44, IVF/endocrine 59; OB Clinic 36.
d) Outside providers:  Quad Cities 47; Des Moines 3; Ottumwa 1.

Ottumwa was not officially part of the pilot program; however, this sample was received in January 2003 before the pilot ended and so was included.

- Statewide Program (began January 15, 2003)
  a) Ethnicity:  Samples were received from 72 European Caucasians; 1 Ashkenazi Jewish; 1 Hispanic Americans; 1 African Americans; 1 Asian Americans.
  b) Family History:  3 women with positive family history; 2 men with positive family history
  c) All partners of individuals with a family history were screened negative.

- Screening Results:
  a) 2 carriers detected among initial samples
  b) no carriers detected among partner samples

- Providers from UIHC:  FDT/Genetics 25; IVF/endocrine 15; OB clinic 10
  Outside providers:  Quad Cities 9; Des Moines 1; Ottumwa 0; Cedar Rapids 17.

*Samples from these cities were all from one practice.
Karen Brewer stated that since the testing is not longer free, fewer tests are occurring. The fee for genetic testing is now $197 per couple.

VII. EXPANDED MSAFP SCREENING PROGRAM REPORT Roger Williamson
Roger provided the group with a handout containing the following data.

Elevated MSAFP:  15,387 total samples
- High 205
  Amnicentesis 7; Ultrasound Only 86; Unknown 112
- Abnormalities
  Anencephaly 5; Open spina bifida 3; Gastrochisis 4; Anhydramnios 1; Anhydramnios 1; Trisomy (18) 1
- One case of the open spina bifida was detected per 68 women with persistent MSAFP elevations.
- One cause of open spina bifida or anencephaly was detected per 26 women with persistent MSAFP elevations.
- One in 15 patients with elevated MSAFP values carried a fetus with a defined fetal anomaly.

The total samples for 01-02 are 15,387. Roger mentioned that there are some pockets within Iowa that do not utilize the testing services. Only 1% of women undergoing screening had persistently elevated MSAFP values.
The program will soon be able to report Quad Screen results. The addition of inhibin to the current panel of three markers will reduce the screen-positive rate of Down syndrome and reduce the number of women receiving the recommendation for amniocentesis. Roger is going to talk with Mason City about screening their patients through the state program. He will update the Expanded MSAFP Screening Program figures in October. The Iowa Birth Defects Registry is performing follow-up for the program.

VIII. WRAP-UP
The next meeting will be in October at 1:00 p.m. in the Well Fargo Bank conference room. Tonya asked if the 2nd week of each month would work for everyone in the future. Shelley mentioned that it would conflict with her and Jeff Lobas’ schedule. The attendees will be polled electronically to see what Friday in October works best.

ADJOURNMENT
The meeting was adjourned at 4:07 p.m.

Minutes respectively submitted by Sherry Smith.