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

MEMBERS PRESENT:
James Matsuda, Neil Mandsager, Celest Johnson, Val Sheffield, Pat Murphy, Amanda Ragan, Andy Penziner on behalf of Jeffrey Lobas, Peggy Stokes, Linda Brown, Jolene Johnson, Celest Johnson, Christina Trout, and Molly Guard

MEMBERS ABSENT:
Paul Romitti, Nancylee Ziese, Roger Williamson, Jerry Wickersham, Gregory Gavin, Rebecca Boyd Dublinske, Michelle Hall, and Mary Gilchrist

OTHER ATTENDEES:
Julie McMahon, Stan Berberich, Tonya Diehn, Tammy O’Hollearn, Dawn Mouw, Judy Miller, Pam DeBoer, Carol Johnson, Cathy Evers

NEW MEMBERS:
Tonya introduced the newest member to the Advisory Committee, Amanda Ragan. Amanda is a Senator from rural Iowa, Mason City area. Amanda shared that she is the Director of two non-profit corporations in the Mason City area. She also oversees a community kitchen.

APPROVAL OF MINUTES:
Tonya noted that the minutes from the October 25, 2002 had been e-mailed out and asked if there were any changes. No changes.

Motion to approve the minutes was made by Linda Brown
Seconded by Julie McMahon

I. COORDINATOR UPDATE/ANNOUNCEMENTS
Tonya Diehn

- University of Iowa press release today in recognition of National Birth Defects Prevention Month.
- Birth Defects Prevention Month is throughout the month of January. Tonya reported that she had put together a proclamation and sent it to the Governor’s office to be signed in December, but had not heard back. Tonya will let everyone know when she finds out the date of the signing. **Update: The proclamation has been signed. The Governor’s January schedule did not permit an official presentation and signing.**
- Birth Defects Prevention Month Activities:
  - Table tents were placed in the cafeterias at the Iowa Department of Public Health, the Capital, and University of Iowa Hospitals and Clinics. The table tents showed a baby, provided some statistics about birth defects, and the benefits of folic acid.
  - Folic Acid Flyers were put in mailing to dieticians and will be put in mailings to physicians, etc. If anyone on the advisory would like flyers, contact Tonya.
• Iowa Birth Defects Registry is giving small bears to local hospitals around the Iowa City area; an effort brought forth by Sandy Gay of the IBDR. She will hear from Proctor and Gamble in the next week to see if they will contribute money towards this effort. If they do, the bears will be distributed statewide. There is a card that goes along with the bear with the registry name and logo.

• Sandy Gay also was able to put a PSA in community Penny Savers newspapers. The newspapers are distributed throughout Iowa and several other states. The PSA message is the same as the one on the PSA table tents. Examples were shared with the attendees.

• On January 15, 2003, the Expanded Maternal Serum Alpha-Fetoprotein Screening Program began routine Cystic Fibrosis carrier screening. The program was also to begin performing the Expanded MSAFP/QUAD screen on this date.

• A volunteer Request was made for the Maternal and Child Health Advisory Committee. The committee meets quarterly. Jeff Murray was the representative for the Birth Defects Advisory Committee, but since he no longer is on the committee, a volunteer is needed. If anyone is interested, contact Tonya.

• Heather Adams, IDPH Assistant Attorney General put together a position paper on HIPAA privacy rules and the Iowa Birth Defects Registry. The paper was distributed to the attendees.

**Regional Genetics Consultation Service**

Cathy Evers

Cathy reported that they are no longer sending out the clinic schedule to physicians, clinics, etc. like they have in the past. They are doing this to save money in light of the budget cuts. The Regional schedule is posted on the Center for Genetics website and they sent out a postcard telling physicians how to obtain it. If you wish to view it, go to [www.idph.state.ia.us/fch/fam_serv/genetics/consultation.html](http://www.idph.state.ia.us/fch/fam_serv/genetics/consultation.html). Val Sheffield also recommended that a mass e-mail could go out in the future.

**II. IDPH UPDATE**

Julie McMahon

Dr. Gleason left the Department of Public Health to become Governor Vilsack’s Chief of Staff. This is a positive step for the Department since Dr. Gleason truly understands Public Health, the infrastructure and the programs. Jane Colacecchi is currently the interim director for the Department. Julie commented that Jane takes a team approach to both leadership and management. She is doing a great job of working with the executive staff and keeping them informed.

Governor Vilsack did place an ad in the newspaper for some Director positions including the Department of Public Health. The resumes were due this past Monday. Julie reported that she would anticipate that there would be Director in place by the next advisory meeting.

IDPH is being conscience when it comes to hiring staff due to budget constraints, as well as in anticipation of the new administration. IDPH presented a level funds budget for 2004. Julie reported that she doubts that there will be a chance to restore funding cuts from the previous years. Approximately 79% of the public health funds are contracted out to the local PH entities or providers in the community. There is currently no room for additional de-appropriations. If IDPH would be required to make budget changes this fiscal year, contracts and personnel would be affected. Julie reminded everyone that most of the department’s funding comes through grant funding at the federal level.
Julie reported that each department is developing performance measures to that will be used as a piece of the Accountable Government Act.

One of the issues on the Leadership Agenda from Governor Vilsack’s Condition of the State Address was health care. Julie reported that this is positive, however, the examples used were mostly acute care, Medicaid, and disabilities.

Christina Trout asked how they would be notified and when, if additional funding cuts were made. She shared that last year she learned through e-mail by a parent versus the Department of Public Health. Julie reported that this year we hope to learn of this information sooner and if necessary, we sometimes have to use e-mail to get the word out quickly. Julie stated that we should know something in March or April for 2003 and not until May for 2004. She said that we are hopeful to stay at level funding for 2004. Julie also requested that the advisory committee be put on the list for the Legislative Update. It comes out every Friday, so they can track bills that they are most interested in. To view legislative updates, click on http://www.idph.state.ia.us/legis/list.htm.

III. MARCH OF DIMES (MOD) – PREMATURITY CAMPAIGN  
Molly Guard

The Prematurity Kick Off is February 5, 6 and 7, 2003 in Des Moines, Iowa City, and Davenport. This is a five-year, 75 million dollar campaign. The advisory committee watched a video that MOD has out about prematurity. MOD has PSA’s that will be out shortly.

MOD is still working toward additional funding for the Iowa Birth Defects Registry. February 19th from 7 until 9 a.m. is MOD lobby day. Pat Murphy and Amanda Ragan will move forward on a bill for the Registry. Molly will keep the committee informed of developments.

IV. NEW ERA IN NEWBORN SCREENING:  
Tonya Diehn

We viewed a portion of a video provided by the CDC, “Saving Lives, Improving Outcomes”. It was a testimonial from a parent with a child with medium chain acyl-CoA dehydrogenase (MCAD) deficiency. Judy Miller reported that two babies have been identified through the Iowa Neonatal Screening Program with MCADD. One child, we follow through Illinois and one was identified during the pilot study. The Metabolic Clinic also follows a teenager with the disorder. The incidence of the disorder nationally is 1 in 15,000.

If anyone would like to borrow the video please contact Tonya, Tammy or Dawn.

V. NEUROMUSCULAR AND RELATED DISORDERS PROGRAM  
Christina Trout

The Neuromuscular Program annual report was distributed. The program has experienced a one percent increase in the number of referrals for one year, but a fourteen percent increase over the last eight years. The onset of these disorders is typically at birth or within the first five years of life. The children are very involved medically requiring a great deal of medical case management. Patients are living longer, as well. The average life span of a child with Duchenne in the past was age fourteen or fifteen and today it is currently 24 or 25 years of age. Christina stated that while they typically see the patients with Duchenne’s twice per year, the number of new referrals is going up. When possible, Christina tries to refer the patients to local community services or service providers. Christina also noted that more patients are using the Neuromuscular Program because the services are not readily available in the community. There
are very few pediatric neurologists specialists for these types of disorders. Adult neurologists are often very uncomfortable working with children.

Currently they provide outreach clinics in Des Moines (4), Mason City (2), Dubuque (1), Waterloo (2), and Sioux City (2). They also have a weekly clinic at the U of Iowa Hospitals every Tuesday. See table 4. Most of Christina’s time is spent on anticipatory guidance and case management. Most recently Christina has seen an increase in calls from SW Iowa and she reports that they are not sure how they will handle this. Added a staff nurse, RN, to help triage phone calls and get information back to families, etc.

Child Health Specialty Clinics assists with scheduling, administrative activities, and charts. Christina reported that this might change as their budget also endures cuts. Neuromuscular has not had the opportunity to do any more analysis or evaluation about their program due to time and money constraints. They are tracking their phone calls to better describe the services that they provide.

Education is provided in a couple of ways. They try to provide this education at the clinics so that people get a first hand look at what they do. Provide lectures to AEA’s and others also on request.

Their budget decreased last year from $115,000 to $104,000. This supports twenty percent of Dr. Matthews’s salary; 100% of Christina’s; 20% for Staff Nurse (1 day/week). They have no support for secretarial staff. They try to pay for this through money recouped through Medicaid. Christina reported that if things continue the way they are, they would be $8,000 dollars in debt by the end of the year. They have not sought out more funding because those that work with this program have no more time to give. They are already working 50-60 hours per week. MD Association provides patient education materials. Christina said that they often direct families to the Internet for educational materials.

Christina reported that they recently applied for a grant through CDC to evaluate counseling with patients and the impact of this on families and the child’s condition. CDC did not fund initially, but indicated that they are interested in the project and may still award the funding in the future. Christina worked with Paul Romitti and Dr. Matthews to secure a grant through CDC for long term follow-up and surveillance of children with Duchenne’s and Becker’s Muscular Dystrophy. The grant will pay for 10 to 15% of Christina’s salary. The grant brings additional responsibilities when they already work at 100% and more effort.

Dr. Val Sheffield indicates that Regional Genetics Consultation Service is also seeing a greater demand for services. He shared with the group that Christina received the highest rating for preceptor in the Medical Genetics course.

Christina estimated that the Neuromuscular Program income is $20,000. Many patients have primary insurance and ill and handicapped waiver. MDA will be pay balance of patient’s bill before sliding fee scale. Families are resistant to going to adult services.

VI. NEONATAL METABOLIC SCREENING PROGRAM UPDATE

Stan Berberich

Stan did not have the final 2002 data to share with the advisory committee. However, he did share that a look at preliminary figures indicated the number of newborns screened and the number of disorders confirmed were similar to last year.
Pilot Study for Expanded MS/MS: Modifications in the lab have been completed so that they have a second MS instrument. This is beneficial for many reasons. If they should have a problem with a specimen, batch, or sensitivity, they can look to see if it is the instrument or other issues. Provides the ability to continue the testing if one of the machines is down. The second machine will assist in reducing the turnaround time. Currently, the screening report is not sent out until all tests are completed. If they get a positive test for a disorder, they call immediately. The majority of results are reported out by the third day. All results reported by five days except a handful, with the latest being eight days. The additional days may be related to days when the instrument is down. The goal is for both of the instruments to be running and routinely used.

The vast majority of abnormal results followed up are “biological abnormal.” This means that the analyte level is abnormal but there are no clinical manifestations. The Neonatal Metabolic Screening Program would like to follow-up these cases to see if clinical significance develops after neonatal period or not. Stan noted that because of the CDC Tandem Mass Grant that Tonya got, they will now be able to look further at follow up and also monitor borderline screens.

Stan reported that he recently had been at the third annual MS/MS Implementation conference in California. He stated that nationally, there is an attempt to get states to share information as it relates to borderline, false positives, cut off rates, and so on. There is a need for collaboration and education because a single program cannot get enough data to determine incidence and clinical validity. Stan reported that he was able to share information about Iowa’s Screening Program in Berkeley, California.

Expanded MS/MS panel methodology for Iowa was determined through our work with MCADD. During our pilot study, we can determine more appropriate cutoffs, reduce false positive rate, and determine which analytes to include and which to exclude. The second goal of the pilot study is to look at how we can confirm these screening results and follow up right away with families prior to clinical onset. The program and other NBS programs are looking at strategies for early identification and treatment. Stan also spoke of follow up being so time intensive for abnormal screens found on the Expanded MS/MS. Currently there is no charge for a repeat screen when an abnormal is detected. There is a cost for any additional testing necessary for confirming a disorder. Currently, the program tries to work with the families regarding insurance to get reimbursement for the additional screening.

Linda Brown asked where the lab is at with using Tandem Mass Spectrometry. She also asked about the impact on families and F/U staff, emotionally and financially. Stan discussed that the program has a responsibility to control the number of false positives and have quick resolution of concerning results. Stan reported that they just got the back up instrument in place. Within a short period of time, they will be using that to run for PKU screen. They will have the capacity to run five times the screens that they run now. Linda also asked what the target date was for the pilot? Initially at least one year. Started this in October 2001-it should be ending shortly. He may assemble another committee to look at the outcomes of this pilot and then report back to the BDAC members.

Stan spoke of the screening that the lab does for other states. They currently screen for North Dakota. Stan stated that the shipping regulations are in flux, which may affect the delivery of specimens from outside of Iowa. Stan reported that currently they receive the specimens within 3 days. Mail service shipping regulation changes may make NBS collection forms biohazardous specimens. If that would happen, it would have a significant impact on their budget.
Stan reported that Nebraska recently put out an RFP for a single laboratory to perform all of their newborn screening. The University Hygienic Laboratory is responding to that RFP. If the lab were to get this screening contract, it would help to keep costs down in Iowa. North Dakota currently attributes 20% to our cost of instruments, staff, and the pilot studies. Stan thinks that states will continue to look at more resource sharing in a time when budgets are being cut and the economy is weak.

VII. GENETICS IMPLEMENTATION GRANT ACTIVITIES

Newborn Metabolic Screening Match

Dawn Mouw

Dawn gave an overview of how she uses the birth certificates to match the screening results. Iowa compares birth certificate records with newborn metabolic screening records. The goal is to improve the Department’s accountability for metabolic screening of all newborns in Iowa.

Screening Reports are downloaded from the lab and birth certificates from vital records each month into an excel spreadsheet. This was a temporary measure until the new electronic birth (EBC) certificate process begins. Due to the fact that the EBC will be delayed, we are currently working on converting the spreadsheet into Sequel, which will better enable us to track the screening.

Once the files are downloaded, they are matched by four criteria. This includes individually, possible matches, matched by baby’s date of birth, and then by the mother’s first initial. Once the matches have been completed a report is generated from the spreadsheet to identify babies not matched and the facility where they were born.

The individual in charge of newborn metabolic screening for the facility will be contacted and asked to provide information about the infants identified through our matching process as not being screened. The contact person will be faxed or emailed a letter asking for their assistance in determining the reasons a newborn metabolic screen was not performed and some additional information to assist in the follow-up of infants not tested at their facility. The facility response will be entered into our spreadsheet.

Newborn screening programs in surrounding states will be contacted for those infants identified by birthing facilities to have been transferred out of state. We are also comparing SIDS death records with newborn metabolic screening records to determine the number of these deaths without screening results. Dawn has contacted Stephanie Pettit with the Child Death Review Team. Stephanie stated that many times the death review team may change the cause of death. If Dawn is reviewing the vital records information the cause of death may change upon the review by the Child Death Review Team. Dawn will send a report of all child deaths to the review team. Stephanie Pettit will let us know if any of the babies may have died due to a birth defect, genetic or metabolic disorder.

Dawn has been working with Tonya on creating a mechanism to exchange screening records between the Border States. The results of Iowa babies screened in South Dakota are being sent to the follow-up consultants and Dawn. Nebraska will provide results upon request. We will continue to build a relationship with the bordering states and their screening of Iowa babies.

Dawn also discussed a recent talk she gave in Norwalk to 190 sixth graders about birth defects and disabilities. She shared one example of what she provided as “hand-on” learning experience for the kids. She also provided the thank you notes that the kids wrote after the school presentation for the board to review.
Tammy summarized the activities that have occurred since the last BDAC meeting. A work group of parents and professionals across Iowa and across the various disciplines was established and met for the first time in September 2002. Participants included parents throughout the state of Iowa, pediatricians, social workers, service providers, attorneys and staff from the following agencies/programs: Area Education Agency, Early ACCESS, Child Health Specialty Clinics, Iowa Department of Public Health, Iowa Birth Defects Registry, Department of Human Services and Parent Training and Information Center, Parent Educator Connection, and genetic service professionals. This group met once per month through the month of December. The work group revised a notification letter, developed a frequently asked questions sheet, resource brochure, and a response card.

At the same time, Tammy reported holding focus groups for parents in six different locations across the state; Council Bluff, Des Moines, Dubuque, Mason City, Ottumwa, and Spencer. There were anywhere from 2 to 8 participants at each of the locations. Parents readily offered revisions to the various documents and talked about follow up, what they thought it should be and things to avoid, letterhead, and so on.

The materials have been reviewed by the document review at IDPH, the assistant attorney general for the Iowa Department of Public Health and most recently by the Iowa Birth Defects Executive Committee. Final finishing touches are being done on the resource brochure.

Tammy has meetings set up to finalize the plans for follow up. She reported that she will be calling all families who have children who are listed within the birth defects registry; approximately 1650 families per year. Tammy explained that all families will get the telephone call unless they return the response card which gives them the option of no further follow up.

VIII. WRAP-UP
The next meeting will be on April 18, 2003 at 1:00 p.m. at Wells Fargo Bank conference room.

VIII. ADJOURNMENT
The meeting was adjourned at 3:45 p.m.

Submitted by Tammy O’Hollearn