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:  
James Matsuda, Brad McDowell (representing Paul Romitti), Nancylee Ziese, Carol Johnson (representing Val Sheffield), Debra Schutte, Gregory Garvin, Andy Penziner (representing Jeffrey Lobas), Peggy Stokes, Christina Trout, Molly Guard, Diana Fritz Cates, and Stan Berberich (representing Mary Gilchrist)

MEMBERS ABSENT:  
Neil Mandsager, Celest Johnson, Jolene Johnson, Roger Williamson, Robert Lee, Shelley Ackermann, Representative Pat Murphy, Jerry Wickersham, Senator Amanda Ragan, Linda Brown, Jolene Johnson, and Michelle Hall

OTHER ATTENDEES:  
Julie McMahon, Tonya Diehn, Tammy O’Hollearn, Dawn Mouw, Pam DeBoer, Cathy Evers, Carney Derksen, and Sherry Smith.

NEW MEMBERS:  
Deb introduced the newest member to the Advisory Committee, Diana Fritz Cates. Diana teaches religion and ethics at the University of Iowa. She received her PhD from Brown University. She is also writing a book on ethics and genetics and is very much interested in contributing to the committee.

APPROVAL OF MINUTES:  
Deb noted that the minutes from the July 11, 2003 had been e-mailed out and asked if there were any changes. No changes.

Motion to approve the minutes was made by Nancylee Ziese and seconded by Christina Trout.

I. COORDINATOR UPDATE/ANNOUNCEMENTS  
Tonya Diehn

- Center for Genetics Activities: Handouts were given to all members of the advisory committee. Dawn Mouw brought the most recent edition of the Heel Stick Newsletter for members to view. Tonya encouraged the group to share comments or suggestions with Dawn in regards to future articles for the newsletter.

Tonya asked Tammy to report on the parent notification project. Tammy reported that she has mailed out 331 notification letters since June 2003. She has completed a personal call to all families, except for the last 40 recently mailed. Tammy reported that there has been a few instances where the child has been removed from the IBDR after follow up. Birth records sometimes indicate an initial diagnosis that is later determined by a specialist not to be the case. The Registry performs further review of any cases where the diagnosis is questioned. A follow up letter is then mailed to both the family and physician regarding the outcome. Tammy has not received any negative comments from the
parents but did receive a letter from a doctor who felt she should have received the notification before the parents. A couple of families have been referred for services.

Dawn has been diligently working on the revisions to practitioner’s manual. An expanded screening panel section is being added. The manual will list the three categories of tandem mass spectrometry detectable disorders and then list all the disorders of each category. Individuals can then click on the disorder to go to the page describing the disorder. It is very close to being completed. She hopes to give the manual to the web coordinator by the following Monday. Dawn brought a copy of the information that will be added to the manual, for anyone that would be interested in reviewing it. She also mentioned that the appearance of the web site is going to show a slight change. The web site’s address will be the same. The practitioner’s manual will only be available on the web so that it can be kept up to date. Individuals may download the entire manual or select individual sections to print. If anyone requests a hard copy, it will be mailed to them.

Dr. Matsuda asked about the process for screening babies born out of state. He wanted to know if we could screen them at any point. Tonya and Stan both agreed that we should be able to screen these babies with the recognition that the tests currently being taken are intended for newborns, not older children. We would need to rely on the medical consultants for their interpretations of the results and make providers aware that the specimens are from an older infant and not of a newborn.

- **Administrative rules update and future revision needs:** Tonya discussed that administration rule revisions have been approved. The expanded panel of tandem mass spectrometry detectable disorders has been added. New language was also added to the rules to allow for the long-term follow-up of individuals identified through the Newborn Screening program. Definitions were added to allow for muscular dystrophy surveillance as well. The rules will be effective November 5, 2004. When the rules are posted, copies of the rules will be emailed to the BDAC members.

Tonya mentioned that the current administrative rules regarding birth defect surveillance differ from the Iowa Birth Defects Registry’s policy. The rules discuss birth defects occurring in Iowa are reporting conditions while the Registry’s policy indicates that they collect birth defect information on pregnancies of Iowa residents. The Registry’s advisory committee will review and determine if the administrative rules should be changed or if revisions should be made to the Registry’s policy.

- **BDAC subcommittees:** There are two subcommittees that need to commence. One is the retention policy subcommittee, which will look at the current policy for retaining newborn blood spot cards. They will specifically look at how the Newborn Screening program stores dry blood spots and if the 30-day period should be extended. Tonya and Stan will be on the committee. Tonya asked for additional volunteers to participate in the subcommittee. No one volunteered. Tonya will call some members individually to request their participation.

The second subcommittee is looking at the addition of cystic fibrosis to the newborn screening panel. This committee had been put on hold. Stan will be attending the CDC and Cystic Fibrosis Foundation cystic fibrosis newborn screening meeting in mid November. The subcommittee will be brought together after this meeting so that Stan can share the available information. Tonya would like to reconvene that group using the same members as before.
Cathy presented the Regional Genetics Consultation Service FY 2002-2003 report. She felt it was important to discuss the clinic activities because that is the main focus of the program. The clinic activity shows the amount of patients that have been seen at the clinic. Although the amount of clinics have stayed the same, the number of people seen in the clinic has dropped 10% due to the shortage of staff and policy changes regarding the number of patients seen each day. Patient cases are more complex and require more staff time. The priority of the clinic has changed. Patients are being seen less frequently for follow-up in order for the clinics to see more new patients. This new policy places the responsibility on the local physicians to assume more of the care of people who have common genetic disorders such as Down syndrome and neurofibromatosis. The referrals from local doctors make up 70% of the patients seen at the clinics, and 19% are self-referrals. Stan asked Cathy if there are fewer patients needing to be seen. Cathy indicated that the number of patient referrals has increased and there is a huge backlog. The policies have been changed so that the number of patients seen is appropriate for the available staff. Cathy also mentioned the importance of the genetic clinic locations to allow convenient access for Iowans within different areas of the state. Julie asked about telemedicine and its utility for RGCS. She mentioned that Senator Harkin is very interested in telemedicine.

There are seeing an increase in patients with adult onset disorders. Currently 22-23% of their patients are over 18. The program has also seen a big increase in referrals for cancer counseling.

The RGSC reduced the number of its educational presentations from 109 to 65.

Cathy discussed financial and insurance issues. The program is state funded. The program also uses a sliding fee scale for those families who may qualify for financial assistance. If a patient has insurance, the insurance company is billed first. Insurance coverage is a constant battle. Carol Johnson specifically discussed difficulties with Coventry. Then the sliding fee scale is applied. Most of the patients seen qualify for either free visits or reduced fees. Many of their patients are on Medicaid. MAC claiming dollars for Department of Pediatrics will be significantly reduced this year. MAC claiming currently funds 1 RGSC counselor. MOD funds 1-800 number and translator services.

The Regional Genetics Consultation Service will no longer see out of state patients. These patients will be referred to the U of I genetics clinics or to their own state programs. Since the Regional Genetics Consultation Service is state funded, services will only be provided to those living in Iowa. Greg Garvin indicates that he refers his Illinois patients to the Peoria genetic clinic.

Clinic changes for FY 2004: Fort Dodge clinics will be reduced. Davenport will be reduced by 2 clinics and Sioux City by 1. The number of Waterloo and Des Moines clinics will be increased. Deb asked if RGSC could hold nurse/genetic counselor clinics only.

II. BIRTH DEFECTS INSTITUTE CODE REVISIONS/NAME CHANGE SUBCOMMITTEE/GROUP DISCUSSION

 Deb Schutte provided a brief overview of why a subcommittee was convened to look at a name change for the Birth Defects Institute (BDI) and possible code revisions. Tonya initially met with Representative Heddens after she introduced legislation to change the name of the Birth Defects Institute and the Iowa Birth Defects Registry. The subcommittee was convened to evaluate the Birth Defects Institute purpose, mission and activities. Deb reported that the
The subcommittee had a couple of goals: 1) Address the current programming of the BDI; 2) Look to the future and possibly expand the code so that there is an option for additional programs and 3) To ensure that the code reflects that programs within the BDI cover the life span for individuals and families as it may relate to genetic conditions. Members of the subcommittee met four times since July. If approved by the committee, Tonya will meet with the IDPH legislative liaison to determine if they can still be moved forward as a technical amendment or if they would need to be introduced as a legislative bill.

Christina Trout inquired why the term “genomics” would be used rather than “genetics.” She felt that the term may be confusing to the basic person who may not be familiar with the new term and that it may be somewhat intimidating to them. Nancylee speaking as a parent, layperson stated that “genomics” is a new term carrying less negativity than the term “genetics.” She also feels “genomics” is a futuristic term, will cover a broader area, and be less limiting. Deb mentioned that there is a tool kit available for the families or anyone else who does not understand the term “genomics.”

Stan stated that using the term “genomics” within the code changes the scope of items that the committee may be asked to consider, (i.e. age of patients, cancer, …etc).

Stan, Nancylee, and Deb feel that using a broader term will be less restrictive and will keep the doors open for future expansion to cover other disorders that may not be mentioned at this time. Stan also mentioned that the arena the BDAC is in does cover a broader area than what is mentioned in the current code. However, using the term “genomics” will help to embrace the concept and opportunity to reframe health, not just defects. Brad inquired if the Birth Defects Registry would be specifically covered in the code. Tonya mentioned that the wording of the code for registry was kept and is in 136A.4.

Greg Garvin stated that he kind of liked the proposed name. He didn’t feel that is was anymore confusing than Birth Defects Institute. Andy mentioned that he liked the sections but questioned the intent and need for 136A.7. This section was unchanged from the original code. Greg Garvin thought that intent of 136A.7 could be to reduce duplication. Tonya will review with Heather Adams.

Greg Garvin moved forward the code revisions. Nancylee seconded the motion. The motion passed unanimously.

Stan motioned to have Jeff Murray to review the draft of the proposed code before it is moved forward. Julie asked Stan if he wanted Jeff to review the entire proposed code, or just certain areas. Stan would like Jeff to review the code to make sure it’s appropriate. Julie stated that IDPH would have Heather Adams, assistant attorney general, review the code as part of the review process. There was discussion about Stan’s motion.

A revised motion was made and approved to have the geneticists’ representatives on the Birth Defects Advisory Committee review the draft prior to moving the revisions of the code forward for technical amendment. The subcommittee would review their comments. It was recommendation to move the proposed code forward with full recognition that the wording may be changed during the legislative process. As long as there are not significant changes, the document will be moved forward. If substantive changes were made, the subcommittee would determine next steps.
Christina gave a brief history of the Neuromuscular Program and the types of services that are available. The program was first introduced in the 1970’s by a famous geneticist, Hans Zellwegger. The program has been administered through the Birth Defects Institute and benefits from the interaction of the other agencies, including the University of Iowa Hospitals and Clinics, childhood specialty clinics, Regional Genetics Consultation Service, Iowa Birth Defects Registry. Other private organizations such as Muscular Dystrophy Association are also involved with the Neuromuscular Program.

The report is based on the following areas:

- Utilization of neuromuscular services, including diagnosis, therapy and care management.
- Evaluation of existing services to assess quality, effectiveness, and impact on the populations served.
- Identification of underserved and at risk populations.
- Development of recommendations, priorities, and proposed strategies to address identified needs, unmet needs, and gaps in service.
- Assessment of educational services to the general public, health care providers, and others as they pertain to neuromuscular and related disorders. Each area of focus will be followed by information that describes the Neuromuscular and related disorders.

The primary purpose of the program is to provide neuromuscular health care services, case management, and education for individuals in families with neuromuscular disease within the state of Iowa. The secondary purpose it is to provide education and information regarding the neuromuscular disorders to healthcare providers, educators, and others. The focus has been primarily on the first purpose.

The number of times each patient is seen annually varies according to diagnosis and stage of illness. Patients with rapidly progressive disorders are evaluated every 6 months, while others with more stable conditions are seen every 1-2 years. The number of patients has increased this year to 506, which is compared to the 439 patients that were seen last year. The INMP primarily provides services for children; however, adults with these disorders are evaluated and treated.

Clinics are generally held weekly at the University of Iowa Hospital and Clinics, and at eleven outreach sites. The contract agreement between the IDPH and the NM Program states that the NM Program must provide at least 40 clinics per year. This number has been met with 53 scheduled clinics last year. Patients are also seen on non-scheduled days to minimize inconvenience to families having to schedule and coordinate visits with more than one physician/specialist.

The number of patients seen at the clinic is increasing. Individuals with complicated and life-shortening disorders (including neuromuscular diseases) are living longer and taking advantage of more sophisticated and aggressive medical intervention. Christina mentioned that although patients are living longer, that does not necessarily mean a high quality of life for the patient.

The Neuromuscular Program’s proposed budget for FY 2004 was submitted to the Iowa Department of Public Health by the University of Iowa, Department of Pediatrics. The Neuromuscular Program appropriations ($104,973) covers 20% of the physician salary, 75% of the primary Neuromuscular Program nurse and the hourly wages of the staff nurse. The
secretarial support, telecommunications costs, travel, paper/copying/equipment supplies are minimally supported by the Neuromuscular Program’s income. These efforts and supplies are primarily donated by the University of Iowa Department of Pediatrics.

The NMP program and the Iowa Birth Defects Registry are working together on a federally funded initiative for Duchene and Becker muscular dystrophy surveillance. They are establishing a registry of all affected Iowans with Duchene and Becker type muscular dystrophy as well as collecting information about what interventions they have had, where they're receiving their services, and what complications they've had with their health. This information will be reported to the Center for Disease Control. This initiative will pay for a nurse to help coordinate this research project and related activities.

Christina discussed billing procedures. When a person receives neuromuscular services through the University of Iowa or their outreach clinics, the patient’s claims are first submitted to their private insurance and/or to Medicaid. Whatever Medicaid pays, that is what the program accepts. If the claim goes to a private insurance, the Muscular Dystrophy Association will pay for remaining fees that are not covered through the patient’s private insurance. Unfortunately, that funding does not necessarily go back into the Neuromuscular Program. Patient fees do not adequately support the program.

Christina discussed one example of a patient with Duchenne and Becker Muscular Dystrophy who needs 24 hour care, but is running out of services because he is passed the age of 18. The state will not pay for the CNA who has volunteered to take additional training in order to take care of the patient’s tracheotomy because state licensing laws require someone with more extensive training, such as an RN or LPN. He is facing the decision of entering a nursing home, or staying home without care because he is unable to pay for home care services. Since people are living longer, it’s more difficult to provide the services and equipment needed by each patient. The program is looking to the state government for additional funding for healthcare services and equipment.

Someone asked if the report information from Cathy and Christina could be provided to legislators. Julie mentioned that Representative Heaton would be visiting public health next week; she will provide him with the information at that time.

BDAC members indicated that they would like Neuromuscular Program and Regional Genetics annual reports on the Birth Defects Advisory Committee web page.

IV. IDPH LEGISLATIVE AND BUDGET UPDATE  
Julie McMahon

Julie mentioned that proposed legislation to merge Department of Human Services and Iowa Department of Public Health was not voted on during the last legislative session. Both departments were directed to prepare/submit a joint report on where the two departments collaborate, where there are potentials for collaboration, and their recommendations for a merger. Both departments have recommended there not be a merger. The joint report was provided to the government oversight committee on September 16, 2003. The committee has asked for additional information. The narrative section of the report is posted on the IDPH web under the legislative updates.

IDPH is finalizing their legislative agenda. This is the first legislative agenda prepared by the Iowa Department of Public Health. Julie feels strongly that under Director Mary Hansen's direction, IDPH will be able to put these issues out there and talk about what health means to the economy as well as to the state of Iowa.
By October 1, every department is required by state law to submit a budget request for the next fiscal year. The Iowa Department of Public Health submitted a status quo budget for FY 05.

IDPH has completed service packages for a number of programs to address critical needs that aren't being addressed with status quo funding. The impact statements will be sent to the Department of Management.

V. INTEGRATED BDI PROGRAM BROCHURE

Tammy reported that each year Wellmark offers large grants for various initiatives, but this year they are offering mini-grants. Tammy would like to apply for a mini grant to develop an integrated brochure for all five programs. It would be convenient for individuals to have appropriate information in one brochure that would consist of all five programs and also reflect how the different programs connect and interact with each other. Each program would still have their own brochures describing what they do. Tammy wanted to have the committee's feedback and opinions on the proposed brochure. She also mentioned that a display for educational outreach would be beneficial at the same time. Since the Center for Genetics and the BDAC are considering the name change and amendment to the code, it would be a good opportunity to provide some education/outreach on the new name and programs of the BDI.

Motion to approve the application for the Wellmark mini grant was made by Peggy Stokes and seconded by Christina. Motion carried.

Tammy discussed the resource brochure used for children with special health and education needs. This brochure is sent to the families for parent notification. It has had a very positive response and many requests for the brochure. She is currently in the process of printing additional English brochures. She will be placing a print request for the Spanish translation of the brochure next week. She also mentioned that she was in the process of having the notification documents translated into Vietnamese.

VI. WRAP-UP

The next meeting will be on January 16, 2004 at 1:00 p.m. at Wells Fargo Bank conference room.

VII. ADJOURNMENT

The meeting was adjourned at 4:10 p.m.

Submitted by Sherry Smith