## CENTER FOR CONGENITAL AND INHERITED DISORDERS ADVISORY COMMITTEE

### Minutes

**Date:** Friday, August 12, 2005, 1:00 – 4:00 pm  
**Location:** Wells Fargo Bank Sullivan Room 833 4th Ave - Grinnell, Iowa

**Members Present:** Jerry Wickersham, Iowa Insurance Division; Dr. Paul Romitti, College of Public Health; Nancylee Ziese, Consumer; Carol Johnson for Dr. Sara Copeland, Division of Medical Genetics, Medical Director; Dr. Greg Garvin, Iowa Osteopathic Medical Association; M. Peggy Stokes, National Assoc. Social Workers, Iowa Chapter; Christina Trout, U of I Clinical Genetics Staff; Dr. Mary Gilchrist, University Hygienic Lab; Dr. Diana Fritz Cates, Ethics/Bioethics Representative; Dr. Roger Williamson, Maternal Screening Programs, U of I; Dr. Bradley McDowell, Iowa Registry for Congenital and Inherited Disorders; Dr. Lisa Mofle, Consumer Representative

**Members Absent:** Dr. Neil Mandsager, Dr. Robert Lee, Dr. Deb Schutte, Dr. Sara Copeland, Shelley Ackermann, Brian Wilkes, Stephan Bayens, Blythe Stanfel, Molly Guard, Senator Amanda Ragan, and Representative Beth Wessel Kroeschell

**Other Attendees:** Pam DeBoer, ex officio; Elizabeth Dowd, ex officio

**State Staff Present:** Kimberly Piper, Jane Borst

**Committee Vice Chair/Presiding:** Jerry Wickersham  
**Facilitator/Minutes:** Kim Piper

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| 1:00 pm | **Call to Order**  
*Jerry Wickersham*  
- **Introductions**  
- **Minutes**  
- **Announcements** | Meeting called to order 2:15  
Introductions done.  
No minutes available to review. | Will review April and July minutes at Nov. 4 meeting. |
| 1:15 pm | **IDPH Update**  
*Jane Borst/Kim Piper* | Ch. 4 passed reviews without comment or questions.  
Stillbirth program presented. Jane spoke about the stillbirth appropriation, PKU appropriation. Paul addressed the cut to the Registry.  
Jane provided info re: the budget process. Providing budget offers to the Govs. Office for the State’s “purchase.” The issue of “embargoing” (withholding information about) the offers will not be there this year as it was last year. CCID programs will be included in the Early Childhood budget. Christina Trout asked if it would be worthwhile to provide a summary of the programs (what services are provided for the State’s dollars). Jane B. encouraged the programs to submit a summary of their services. | Discussion |
| 1:45 pm | **Introduction of New Members**  
*Kim Piper* | New members were introduced. |  |
| 1:55 | **Nominations/voting for chair & vice chair**  
*Jerry Wickersham* | Dr. Williamson moves to nominate Christina Trout for Chair, seconded by Dr. Garvin. (Both motions withdrawn - withdrawal approved with one abstention.) Dr. Gilchrist has nominated Jerry as Chair. Motion failed for want of a second. Jerry nominated as Chair and Christina as Vice Chair as motioned by Nancylee, second by Mary Gilchrist. Nominations closed. Vote - Jerry as Chair and Christina as Vice Chair approved with two abstentions. | Elected chair – Jerry Wickersham and vice chair Christina Trout for 2006 term |
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<td>2:00 pm</td>
<td>Recognition of out-going members</td>
<td>Linda Brown only outgoing member. Linda will be recognized by Director Hansen, and will receive a certificate of appreciation.</td>
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<td>2:15 pm</td>
<td>Metabolic Screening program Reports/comments &amp; questions</td>
<td>Metabolic Treatment Report: Jerry stated that the name TriMark should be changed to TriCare, and he has contacted TriCare regarding their coverage policy. He will follow-up with Carol. Those uninsured in the program are: two from DSM, one from NE Iowa (Mitchell/Howard County). Carol states they have been able to increase the social worker’s % of effort to 40% (up from 10%). Carol also mentions that she thanks legislators, CIDAC, IDPH, and MoD in a cover letter to this report. Considering changing the name of the program to the “Metabolic Treatment Program,” to better reflect the offering of medical foods and formula as necessary treatments, rather than just nutrition. Neuromuscular Report: Neuromuscular Report: Christina Trout stated that many patients from the West side of the state are seen in Omaha. The Neuromuscular Clinics are running at capacity now, and are considering adding additional clinics to meet the need. There is a shortage of child neurologists in the state. Regional Genetic Counseling Services Report: Clinical Outreach has taken over the scheduling and arrangements of outreach clinics from the Child Health Specialty Clinics. Nancylee questions the RGCS decrease from 990 to 700 patients in the last 4 years. Jane B. recommended on RGCS separating out metabolic clinics from RGCS clinics when counting clients served.</td>
<td>Discussion/question s</td>
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<td>2:45 pm</td>
<td>Center Update</td>
<td>No additional items to report.</td>
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<td>3:00 pm</td>
<td>Plan for coming fiscal year</td>
<td>Kim would like to review and update the State Genetics Plan – making it more of a working document. Kim and a committee will update the plan and present it at the next meeting. Subcommittee members appointed by Jerry: Carol Johnson, Brad Mc Dowell, Linda Brown and Kim Piper.</td>
<td>Kim will set up a meeting of the subcommittee to address the updates to the plan.</td>
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<td>3:30 pm</td>
<td>Additional Items/Next Meeting</td>
<td>Mary Gilchrist wanted to thank Kim Piper for her work to get the Administrative Rules presented and approved, therefore enabling the screening programs to expand their services. Nancylee Ziese has requested that discussion regarding INMSP waivers be held at the January CIDAC meeting. Roger Williamson states that he has been approached by a research study to contribute old MSAFP blood for analysis. He would like to be able to do this, but notes there should be a policy re: the use of MSAFP blood and blood spots from the neonatal screening for research (e.g. analysis of blood spots for environmental markers such as metals, etc.) Roger will speak with California about their policy re: this. The next meeting will be moved to November 4th, due to scheduling conflicts of members. It will be held at the UHL Neonatal Screening lab in Ankeny on the DMACC campus. Tours of the facility will be available prior to the start of the meeting.</td>
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<td>3:45 pm</td>
<td><strong>Adjourn</strong></td>
<td>Motion to adjourn by Peggy Stokes, and seconded by Nancylee Ziese. Motion approved. Meeting adjourned at 3:15 p.m.</td>
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