

Birth Defects Advisory Committee Minutes

October 25, 2002

CALL TO ORDER:

Rebecca Boyd Dublinske called the meeting to order at 1:00 p.m. Rebecca presided over the meeting. Introductions were made.

MEMBERS PRESENT:

Julie Curry, Carol Johnson for Val Sheffield, Molly Guard, Paul Romitti, Jeff Lobas, Rebecca Boyd Dublinske, James Matsuda, Debra Schutte, Roger Williamson, Michelle Hall, Neil Mandsager, Jerry Wickersham

MEMBERS ABSENT: Peggy Stokes, Linda Brown, Nancy Lee Ziese, Celeste Johnson, Pat Murphy, Gregory Garvin, Amanda Ragan, Jolene Johnson, Christina Trout, Mary Gilchrist

OTHER ATTENDEES:

Julie McMahan, Tonya Diehn, Tammy O'Hollearn, Karen Brewer, Dawn Mouw, Cathy Evers, Laurie Loftus, Cheryl Barkau from Coventry Health Care, Marcia Valbracht

APPROVAL OF MINUTES:

July 19 minutes were reviewed. Motion to approve minutes made by Jeff Lobas. Seconded by Jerry Wickersham

I. ANNOUNCEMENTS

Early ACCESS

Julie Curry

Early ACCESS is not a program, but a system of programs. There is an interagency agreement between four different agencies; Iowa Department of Education, Iowa Department of Public Health, Child Health Specialty Clinics (CHSC), and Department of Human Services. Jeff Lobas briefly discussed the relationship between Early ACCESS and CHSC.

A resource manual will be coming out in November and will be available on CD-ROM, hardcopy, and electronically. She will notify BDAC when these manuals become available. These manuals have information on all available programs including the genetics programs.

The 2000-2001 Early ACCESS annual report is available at <http://www.state.ia.us/educate/ecese/cfcs/ea/reports.html>.

Cystic Fibrosis

Michelle Hall

Michelle discussed a recent clinical trial of a new pulmonary treatment approach for Cystic Fibrosis patients. The trial demonstrated that Zithromax (azithromycin) improves the pulmonary function of CF individuals infected with pseudomonas. The six-month double-blinded study indicated that a regimen of the antibiotic three times a week in addition to other medications resulted in a six percent improvement in lung function, a 50% reduction in hospitalization and weight gain. Side effects have been minor. This medication has been covered by insurance if it

being used to treat infection. Michelle is not sure about coverage for preventive measures. She distributed the Cystic Fibrosis Foundation news release.

March of Dimes

Molly Guard

Molly talked about the prematurity campaign that will begin January 2003 and will run for five years. Ed Bell is the campaign chairperson. Press conferences will be held in February 2003 at the following locations: February 5th @ Iowa City, February 6th @ Des Moines, and February 7th @ Davenport. This campaign is going to provide education to the public for prevention measures. They are looking for an ambassador for the campaign and to network with a statewide program.

A \$15,000 Folic Acid Grant has been given to the Iowa Department of Public Health to continue the Folic Acid Council.

II. IDPH UPDATE

Julie McMahon

A handout with the IDPH table of organization, election year changes, budget talking points, and program elimination commission summary was distributed.

Julie understands that there is an offer out for the medical director's position. Dr. Harvey has resigned her position as State Public Health Dental Director and will be going to Broadlawns. She will continue working for the Iowa Department of Public Health in a consulting role until at least the end of the fiscal year about 10 hours weekly.

Julie reviewed the IDPH organizational structure with the attendees. The Department currently has 5 divisions. Division of Tobacco has to be a separate division per Iowa Law. The Tobacco division has taken a huge budget cut of 25.3%. In the Community Health Division, the Center of Genetics and the Bureau of Oral Health have made some advances over the last few years.

This current election will change 40% of our legislative body. There will be a learning curve with the new legislators.

FY 2003 budget funds are as follows: 63%-Federal funds, 16%-General funds, 12%-Tobacco funds, 7%- Other funds, 2%-Gaming or Gambling funds. Of the general fund budget, 8% of the funds are for elderly wellness. There has 9.32% reduction in budget since FY 2002. Over the last 2 years the Department of Public Health's general fund has been reduced by 24.2%. 24.45 FTES have been reduced.

Program Elimination Commission was established. They will submit a report on December 31, 2002 on their findings of their review. From this report, the Legislative Services Bureau will develop a bill and it will be introduced into legislation. This bill cannot be amended.

IDPH will be developing a strategic plan for each division & department in conjunction with the Accountable Government Act. Starting October 1, 2002, there will be a performance contract between any department of state government and contractors. Contractors have to perform up to these measures.

III. COORDINATOR REPORT:

Tonya Diehn

Status report on Administrative Rules:

The maternal serum and newborn metabolic screening changes made to Chapter 4 of the Administrative Rules will be effective November 6, 2002. A provision was added to fund special medical formula as a last resort. Tonya talked about the Des Moines Register article on this funding source. A handout detailing the rule changes was distributed.

Center for Genetics Activities:

Tonya announced some advisory committee changes. Julie Curry will be resigning as the Department of Education representative. Tonya thanked Julie for her involvement in this committee. Jeff Murray has also resigned as the Ethics representative. Tonya asked for recommendations from individuals to fill this position. Amanda Ragan will be the new senator for the Birth Defects Advisory Committee and will start in January.

Tonya introduced two new staff members for the Office of Genetics, Dawn Mouw and Laurie Loftus.

Tonya discussed the Center for Genetics website. There is a Birth Defect Advisory Committee section that includes members and minutes of our meetings. The Iowa Neonatal Metabolic Screening Program section has a health practitioner page. The page includes a practitioners manual with information about each disorder screened, result interpretation, contact persons, and follow-up instructions. Individuals can review each chapter separately or download the entire manual. Program brochures will also be available on the website. There is a vast resource page. If anyone has additions to this page, please let Tonya, Tammy, Dawn, or Laurie know.

Sheryl Stimson (nutritionist), Judy Miller (Metabolic Management Clinic) and Tonya met with Amish elders to discuss new metabolic screening. They were able to meet with 13 gentlemen who asked excellent questions. Currently not all Amish babies are screened. To facilitate the screening process, the Bureau of Vital Records is including a metabolic screening collection form and brochure in their home birth packets sent out to the mid-wife to register the birth.

Birth Defects Awareness Month is coming up in January 2003. Tonya would like to get the Folic Acid Council started. Volunteers are still needed for this committee.

CDC Cooperative Agreement:

Iowa Department of Public Health received a three-year cooperative agreement from the Centers for Disease Prevention and Control to do MS/MS surveillance and long-term follow-up. A handout summarizing the project was provided to the attendees.

IV. REGIONAL GENETICS CONSULTATION SERVICE

Cathy Evers

The Annual report was distributed by email prior to the meeting. RGSC received 418 new referrals in 140 working days, which is approximately 3 per day. There were 79 clinics held in FY 2002. Cathy reported a decrease in clinics due to reductions in staff including one counselor and one physician. Clinic sites in Decorah and Atlantic have been eliminated and clinics in Spencer and Ottumwa have been reduced to 3 times per year. The Burlington site may be reduced to 3 times per year also. Cancer risk counseling and assessment is becoming a significant part of their clinics. There has been a trend of more adults attending clinics who mostly had questions on cancer genetics.

They on average see 11 patients per clinic. The program continues to have a very low no show rate of 5.4%. Physicians are reviewing their follow-up patient load to see if they really need to see them again. The program would like to be a consultation service only and give primary care back to local physician.

RGSC patient fees bring in about \$80,000 annually. A total of approximately 60% of their patients qualify for 100% reduction of fees after using the sliding fee scale. About 15% receive a 25% to 75% fee reduction. Approximately 50% of their clients receive Medicare and/or Medicaid benefits. The revenue covers the cost of medical and office supplies, purchasing and repair of equipment and student salaries.

A grant that was received from the March of Dimes for a statewide toll free telephone line and translator services. Interpreters are used in 30 out of 80 clinics. Cost of interpreters are \$20 to \$45 per hour with a typical session taking about 90 minutes. Two additional grants received from The Children's Miracle Network covers the costs of educational materials and toy purchases.

The program receives state appropriated funding from IDPH for salaries. This funding received a 9.32% reduction. Cathy discussed program changes made. The RGSC will hold 80 clinics. The program will not be hiring another counselor. They have hired a geneticist but are still awaiting approval for him to leave his home country of Jordan. There will be 3.25 FTES genetic counselors or nurses, 1 FTE for physicians, 1 scheduler, 1.66 secretary, .80 program coordinator and .20 data manager. The administrative assistant and director are in-kind contributions. The RGSC schedule will now be on the web and postcards will be sent notifying health care providers of this change. They will now use pool car for clinics. They have reviewed and prioritized education outreach. They are also looking at letter templates, online data collection.

Julie Curry wonders if families could be hooked up with care coordinators for follow-up with physician. Julie McMahon recommended that Center for Genetics, CHSC, Early ACCESS and RGSC get together to determine how we all can help.

Tonya Diehn and Julie Curry offered assistance with distributing the schedule by email. Tonya also offered assistance with clinics if needed.

V. CF CARRIER SCREENING PROGRAM

Roger Williamson

Roger reported statistics on the July 2002 Pilot Project for CF screening. Approximately 200 specimens were received and 91 evaluated. Patients at UIHC, Davenport and Dr. Mandsager's office participated in the pilot study. Four carriers were detected and one carrier couple. Neil Mandsager reported a 15% uptake in his patients. Pilot accomplished goals and was within budget. The program will begin routine screening. A letter will be sent to practitioners. The cost will be \$197.00 for the 25 most common mutations. As far as the issue of insurance coverage, it is believed that the more the necessity, the more likely that the insurance company will cover the testing. Also a family history may be a factor in insurance coverage issues.

VI. IBDR PARENTAL NOTIFICATION SYSTEM ACTIVITIES

Tammy O'Hollearn

Tammy provided information on the workgroup and statewide parent groups that she has set up. Their first meeting was 9-27-02 @ the Iowa Department of Public Health. At their next meeting, which will be October 31, 2002, the group will review a draft of a notification letter and resource manual, and a frequently asked question worksheet.

Jerry Wickersham expressed a concern about insurance coverage questions with families who are notified by the Iowa Birth Defects Registry. He wants parents to know that the Insurance Division is a resource. He suggested that information be placed on the Center for Genetics website in reference to these issues. The Iowa Insurance Division web page is www.iid.state.ia.us.

VI. WRAP-UP

The next meeting will be on January 17, 2003 at 1:00 p.m.

Marcia Valbracht shared with the attendees that the Iowa Newborn Screening Program will be offering an interactive video conference workshop on newborn metabolic screening and blood spot collection. The workshop will be held on November 14 from 12:30 to 3:30 at 15 ICN sites. Individuals can get information by going to www.uhl.uiowa.edu and clicking on upcoming events.

Julie Curry mentioned that her program has received grant for data sharing collaborative. They will be tapping partners and will have 2 FTES for the 18-month project.

VII. ADJOURNMENT

The meeting was adjourned at 3:30 p.m.

Submitted by Laurie Loftus.