

RHODE ISLAND BIRTH DEFECTS ADVISORY COUNCIL

September 30, 1:30-3:00PM

Rhode Island Hospital Child Development Center

MEETING MINUTES

Attendance

 Present:

Dianne Abuelo, MD, Rhode Island Hospital Genetic Counseling Center

Kristine Campagna, VNA of Care New England

Pamela High, MD, Rhode Island Hospital Child Development Center

Francois Luks, MD, Hasbro Children's Hospital

Betty Vohr, MD, Women and Infants Hospital

RI Department of Health Staff: Ellen Amore; Deborah Garneau; Bill Hollinshead; Michele Quaedvlieg; Peter Simon; Samara Viner-Brown

 Absent:

Betsy Akin, Rhode Island Chapter of the March of Dimes

Stephen Carr, MD, Women and Infants Hospital Prenatal Diagnosis Center

Theresa Hancock, Rhode Island KIDS COUNT

Nicole Katzman, Rhode Island Parent Information Network

Geralyn Messerlian, PhD, Women and Infants Hospital Prenatal and Special Testing Laboratory

Ruth Schennum, PhD, Rhode Island Department of Human Services,

CEDARR Family Centers

Richard Smith, MD, Rhode Island Chapter of American Academy of Pediatrics (AAP)

Kathleen Woodruff, MD, Rhode Island Chapter of American College of Obstetricians and

Gynecologists (ACOG)

I. Welcome/Introductions

II. Grant Application to the Centers for Disease Control and Prevention (CDC)

 The Rhode Island Birth Defects Surveillance Program (RIBDSP) is preparing an application to the CDC for funding to expand its surveillance system and program. The application is due October 20th and a summary of the requirements was disseminated for discussion.(see attachment).

 The three main components of the grant focus on the use of surveillance data for improving access to health services and early intervention programs; use of surveillance data for prevention activities; and impact on population-based birth defects surveillance.

Access to Services

 The group suggested that the sentinel conditions pilot will illustrate how Rhode Island's system will improve access to services, since we are tracking cases from screening through referrals via medical records, the Family Outreach Program, and pediatric provider

follow-up. Specific data sources will include the Genetic Counseling and Child Development Centers at Rhode Island Hospital, and the Prenatal and Special Testing Laboratory and Prenatal Diagnosis Center at Women and Infants Hospital.

 Sam mentioned that she and Michele met with Dr. Stephen Carr at the Prenatal Diagnosis Center (PDC) and that a new Fetal Program data coordinator at the PDC will help facilitate the RIBDSP obtaining prenatal diagnosis data.

 The Universal Newborn Hearing Screening, Diagnosis and Intervention Guidelines and Checklist developed by First Connections in collaboration with the American Academy of Pediatrics was distributed. This can be used as a model for the sentinel conditions checklists and will be described in the grant application.

 The following questions were raised: When should a case be reviewed? How long before action is required? What indicators of care should be used? How are services defined, e.g., genetic counseling?

 The Child Development Center (e.g., spina bifida clinic) is a good source of data and information on coordination of specialty care.

 The issue of follow-up and how the RIBDSP will know when children drop out of specialty care and intervention programs was raised.

 The Health Department's new Pediatric Provider Enhancement Project (PPEP) will provide another opportunity to

coordinate service referrals. The PPEP is a demonstration project where parent consultants are situated in eight pediatric practices across the state. These parent consultants help families of children with special health care needs to access the service system and community resources.

• CDC has developed information packets on specific conditions (e.g., autism, Down Syndrome, etc.) for parents of children with special health care needs. It was suggested that parents of children receiving services from the CDC who have provided consent for disclosure may be potential resources for focus groups.

• How will data be updated on conditions; will system print out

Prevention

• The Health Department's Women's Health Screening and Referral Program (WHSRP) provides education and referrals to women who receive free pregnancy tests at Title X funded family planning clinics. While women wait for their test results, they are asked to complete a survey that includes questions on folic acid use, family history of birth defects, and tobacco and alcohol use. By providing education and referrals to women who are pregnant and those who are not yet pregnant, the WHSRP provides an opportunity to help prevent birth defects.

• The RIBDSP collects data on genetic counseling from medical records. A missed opportunities analysis could be conducted regarding genetics counseling to determine what services families of

children with birth defects received.

 The RIBDSP should focus on and define standards of care and system performance

 Need to define genetic counseling in terms of when it is provided, e.g., antenatal, neonatal and/or ongoing. Dates of services and provider information need to be collected.

 Prenatal diagnosis and termination data should be included in the data system.

 What about tracking siblings—KIDSNET is an opportunity to track older children

 KIDSNET provides data on preventive services

 What is the standard for genetic counseling in terms of how many times services are offered?

Other Comments

 It was suggested that GIS be used to map cases in order to determine risk factors, clusters, etc.

 Add prenatal genetic counseling data and demographics to RIBDSP Child Profile

 The RIBDSP does plan to work with other states to develop data sharing agreements to obtain information on Rhode Island children born out of state

 Betty Vohr requested the list of data variables collected by RIBDSP

Action Steps:

 Add prenatal genetic counseling and testing and family history of birth defects to child profile

 Note on profile if services were declined

III. Regulations/Reporting Requirements

 A draft reporting form was distributed.

 As mentioned during the last Advisory Council meeting, the process of promulgating regulations usually takes 4-6 months and requires community input (via mail, e-mail and website posting) and informal community review meetings. Once community input has been incorporated in the regulations, a formal public hearing must be held.

IV. Next Meeting

The next meeting will be held in January 2005

ATTACHMENT:

**POPULATION-BASED BIRTH DEFECTS SURVEILLANCE PROGRAMS
AND THE UTILIZATION OF SURVEILLANCE DATA
BY PUBLIC HEALTH PROGRAMS**

Application Deadline: October 20, 2004

Average Award: \$190,000 (\$150,000-\$220,000)

Award Date: March 1, 2005

Project Length: 5 years (3/1/05-2/28/10)

Purpose

- 1) development, implementation, expansion and evaluation of state's population-based birth defects surveillance systems;**
- 2) development and implementation of population-based programs to prevent birth defects;**
- 3) development and implementation or expansion of activities to improve the access of children with birth defects to health services and early intervention programs;**
- 4) evaluation of the effectiveness of the referral activities and the impact on the affected children and families**

Measurable outcomes to align with NCBDDD performance goal:

 Increase the number of US births covered by birth defects monitoring programs which use these data to plan services for children and evaluate prevention strategies

Recipient Activities (for States with ongoing surveillance systems-Category 2)

a) Broaden methodologies and approaches which will improve and expand the capacity of the existing population-based surveillance system to ascertain cases and generate timely population-based data of major birth defects occurring in the State.

- b) Analyze and disseminate the surveillance data generated by the system in a timely fashion including rates and trends of major birth defects (e.g., publish report on the surveillance data).**
- c) Evaluate the surveillance methodology used.**
- d) Involve the appropriate additional partners within the State, including the State's organization receiving Title V Federal funds, to expand birth defects prevention programs (i.e., Neural Tube Defects (NTD) occurrence prevention). Share results with appropriate organizations within the State and with other States.**
- e) Evaluate the prevention progress.**
- f) Involve the appropriate partners within the State to expand activities to improve the access of children with birth defects to comprehensive, community-based, family-centered care (e.g., establish linkages with other programs like Children with Special Health Care Needs).**
- g) Evaluate the progress on improving access to services (e.g., identification of children and families eligible for services; evaluate the timeliness of referral to services).**
- h) Evaluate the effectiveness of the referral activities and the benefit/impact on the affected children and families.**

Content/Evaluation Criteria

A. Use of surveillance data for improving access to health services and early intervention programs (30 points)

- 1) Ability to integrate programs within the state (MOA/U,**

documentation of numbers of eligible children or families referred for and percent receiving services)

2) Improve and expand approaches to increase identification of children or families eligible for health services.

3) Evaluate the effectiveness of the referral services and the outcomes of children and families who receive services.

B. Use of the surveillance data for prevention activities (25 points)

1) Ability to work with appropriate partners in the State (e.g., provide letters of support, MOA/U).

2) Use of surveillance data to expand prevention programs.

3) Sharing the surveillance data (e.g., personal identifiers and contact information) with programs or agencies so that children or families are enrolled in prevention programs.

4) Evaluation of progress made in the prevention of birth defects.

5) Letter from the State's organization receiving Title V Federal funds that describe the data linkages and other collaborative activities with the applicant.

C. Impact on population-based birth defects surveillance (25 points)

1) Ability to improve/expand population-based birth defects surveillance.

2) Methods of case ascertainment

3) Timeliness of case ascertainment.

4) Level of coverage of the population.

5) Specific birth defects ascertained.

6) Analyzing and reporting surveillance data to appropriate State, local and Federal health officials.

7) Evaluating the surveillance methodology and quality of the surveillance data.

8) The degree to which the applicant has met the CDC policy requirements regarding the inclusion of women, ethnic and racial groups in the proposed research. This includes:

 The proposed plan for the inclusion of both sexes and racial and ethnic minority populations for appropriate representation.

 The proposed justification when representation is limited or absent.

 A statement as to whether the design of the study is adequate to measure differences when warranted.

 A statement as to whether the plans for recruitment and outreach for study participants include the process of establishing partnerships with community(ies) and recognition of mutual benefits.

D. Organizational and program personnel capability (15 points)

1) Whether the applicant has the experience, skills, and ability to develop and improve birth defects surveillance and use surveillance data to develop prevention programs and improve access to health services or early intervention programs.

2) The adequacy of the present staff and/or the capability to assemble competent staff to either implement or improve upon a birth defects surveillance system and develop programs for improving access to health services and early intervention programs. If it is necessary to

hire staff to conduct program activities, provide plans for identifying and hiring qualified applicants on a timely basis. Also, provide plans for how work on program activities will be conducted prior to hiring necessary staff.

3) The applicant shall identify all current and potential personnel who will work on this cooperative agreement including qualifications and specific experience as it relates to the requirements set forth in this announcement.

E. Applicant's understanding of the public health impact of birth defects (5 points)

 The extent to which the applicant has a clear, concise understanding of the requirements, objectives and purpose of the cooperative agreement. The extent to which the application reflects an understanding of the public health impact of birth defects surveillance as it relates to their State.

F. Human Subjects Review (not scored)

 Does the application adequately address the requirements of title 45 CFR part 46 for the protection of human subjects?

G. Budget justification and adequacy of facilities (not scored)