Monday, February 5, 3:30-5:00PM
Concurrent Breakout Session B

Prenatal Diagnosis Surveillance Methods
Moderator: Russell Kirby, School of Public Health, University of Alabama at Birmingham, Birmingham, AL

This session will focus on issues related to the prenatal diagnosis of birth defects, and resulting implications for surveillance programs. First, Dr. Jan Byrne from Utah will discuss prenatal tests and procedures, and their accuracy for different defects at specific gestational ages. Then, representatives from surveillance programs in Arkansas and Puerto Rico will describe their programs' specific methods and experiences with reporting prenatal diagnostic data. Finally, Jan Cragan will review plans for adding a chapter on prenatal diagnosis to the NBDPN Surveillance Guidelines and Standards, and the results of a survey of program directors regarding the content of the chapter. Input from session attendees on topics to be included in the chapter, and discussion about issues related to conducting surveillance for pregnancies diagnosed prenatally with birth defects will be sought.

Prenatal tests/procedures, the accuracy at specific gestational ages for specific renal or other defects
Janice Byrne, University of Utah Health Sciences Center, Salt Lake City, UT

Methods, criteria, reporting, prenatal diagnostic data
Linda Jackson, Arkansas Children's Hospital Research Institute, Little Rock, AR

Puerto Rico Surveillance System efforts for reporting prenatal diagnostic data
Diana Valencia, Puerto Rico Department of Health, San Juan, PR

Surveillance Guidelines and Standards Chapter on Prenatal Diagnosis
Jan Cragan, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, GA

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Working with Family Organizations/Networks Collaboration with Families and External Partners
Moderator: Allison V. James, Arizona Department of Health Services, Phoenix, AZ

Dana Anderson, Down Syndrome Association - San Antonio Chapter
Laura J. Warren, Co-Director, Texas Parent to Parent/Family Voices
Nora A. Oyler, Executive Director, Texas Spina Bifida Association
Ann Andes, Anencephaly Support Group

There are many great opportunities for parent support organizations for families of children with birth defects and birth defects surveillance programs to work together in mutually beneficial ways. The goals of most parent support organizations are to provide information, advocacy, and emotional support to parents. Birth defect surveillance programs work toward very similar objectives: they provide information on the incidence of birth defects, known risk factors, strategies for prevention, and research findings; they promote the use of data in advocacy for improved services for children with birth defects and their families; and they provide referral of families to state and community services for emotional and medical support. Parent support organizations are invaluable to birth defect registries as data users; as resources for information about the efficacy of community services; as avenues to disseminate information about multidiscipinary clinics and other services; for feedback on outreach, prevention, and referral activities; and as advocates at the state legislature for continued support for birth defects registries and birth defect research. Birth defect registries can in turn be invaluable resources to parent organizations as data providers, as voices in state government, as liaisons with health care organizations, and by providing ways to disseminate information about services the organizations provide.

The presenters for this breakout session represent local chapters of national organizations that provide services and support to children with birth defects and their families. They will share information about their organizations, why their organizations were created, what their organization goals are, and what services they provide to children with birth defects and their families. They will also discuss their agenda and goals for the future. Finally, they will highlight opportunities they recognize for birth defects registries and parent organizations to better work together to serve their communities.

Monitoring for Changes in Birth Defects Prevalence
Moderator: Peter Langlois, Birth Defects Epidemiology and Surveillance Branch, Austin, TX

Adolfo Correa, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, GA
Phil Cross, New York State Congenital Malformations Registry, Troy, NY
Russel Rickard, Colorado Responds to Children with Special Needs, Denver, CO

One of the objectives of birth defects registries is to monitor for changes in the prevalence of birth defects. In the past, such monitoring has focused on temporal changes. In recent years, some registries have been able to geocode registry data and started to conduct spatial analysis of registry data. This panel session will present three speakers from birth defect surveillance systems that have conducted temporal monitoring for several years and have started to explore spatial monitoring of registry data: Atlanta, New York, and Colorado. The speakers will consider the following questions:

(1) Why might a registry consider expanding the monitoring for changes in time to include monitoring for variations in space (i.e. geographically) or changes in time and space? What might be some potential caveats of doing so?

(2) What are some practical suggestions for how a registry might do this? For example, what defects should be considered for such monitoring? How often should it be done? Is there a particular statistical approach or software package that the speaker has found works well or does not work well?

(3) If a change is found through monitoring, what steps might a registry consider taking next?

While some theoretical background might be mentioned, we intend to keep this session as practical as possible. However, we are all learning how to do this. So the objective of this session will be to review what people are trying to do and about what approaches might be workable, rather than to provide a recommendation of specific approaches and techniques.