



NBDPN is a network of individuals working at the national, state and local level in birth defects surveillance, research, and prevention. It serves as a forum for exchanging ideas about the prevention of birth defects, developing uniform methods of birth defect surveillance and research, and providing technical support for state and local programs.

About NBDPN



- » **Over 200 members from all states and several countries**
- » **Established in 1997; Incorporated in 2000**
- » **Mission: to establish and maintain a national network of state and population-based programs for birth defects surveillance and research, to identify factors that can be used to develop primary prevention strategies, and to assist families and their providers in secondary disabilities prevention**

NBDPN Objectives



- » **Improve quality of surveillance data**
- » **Promote scientific collaboration**
- » **Provide technical assistance for data collection**
- » **Facilitate the dissemination of information**
- » **Compile and make available state surveillance data**
- » **Use birth defect data for health services planning**

NBDPN Committees



Annual Meeting

- > Plans and arranges the content and structure of the annual meeting of state and national programs working in birth defects surveillance, research, and prevention

Data Committee

- > oversees the collection of the state data for the Annual Report, develops definitions, and coordinates data use and other data-related activities
- > 47 birth defects, data from over 40 states

Education and Outreach

- > Establishes guidelines and develops educational materials that states may use to assist families and their children with birth defects
- > Birth Defects Prevention Month Packet

Ethical, Legal, and Social Issues

- > Examines the regulations that impact birth defects surveillance and the consequences of using birth defects registries

NBDPN Committees



Membership, Bylaws, and Nominations

- > Establishes guidelines and policies concerning NBDPN membership, develops and maintains the bylaws, and oversees officer nominations and elections

NTD Surveillance/Folic Acid Education

- > Addresses strategies for improving state capacity for surveillance of neural tube defects and for promoting folic acid use
- > NTD Rapid Ascertainment Project, data from 26 states

Publications and Communications

- > oversees the publication of the NBDPN Annual Report, a periodic newsletter, and the web site. The purpose of this committee is to improve the dissemination of information from the Network to its members and other individuals (e.g., advocates, MCH/CSHCN directors)
 - + Annual Report in Teratology
 - + Semi-annual newsletter
 - + Web site: www.nbdpn.org

NBDPN Committee



Surveillance Guidelines & Standards

- > **develops surveillance standards and addresses data quality issues and uniform data definitions**
- > **Surveillance Guidelines and Standards Manual, with chapters on:**
 - + **Data Management/Data Security**
 - + **Case Ascertainment Methods**
 - + **Legislation**
 - + **Data Collection Variables**
 - + **Disease Classification**
 - + **Statistical Methods**
 - + **Data Quality**
 - + **Case Definition**
 - + **Data Utilization**
 - + **Data Presentation**
 - + **Prenatal Surveillance**



Membership and contact information

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