

NATIONAL BIRTH DEFECTS PREVENTION NETWORK

-- ORIENTATION PACKET --

Welcome to the **National Birth Defects Prevention Network!**

This packet provides orientation materials to acquaint you with our organization and its functions, and how you can be involved.

We affectionately call our organization the "Network" or "Birth Defects Network." For a real tongue twister we call it the "NBDPN."

MISSION AND OBJECTIVES

The Network began as an unincorporated organization in 1997. In September 2000, the Network became a nonprofit corporation called National Birth Defects Prevention Network Inc. The Network is organized and operated exclusively for charitable and educational purposes within the meaning of section 501(c)(3) of the IRS tax code.

The Network bylaws¹ provide information about our Mission – the promotion of activities to establish and maintain a national network of state and population-based programs related to birth defects. The Network promotes the following:

- Conducting birth defects surveillance and research to assess the impact of birth defects upon children, families, and health care;
- Identifying factors that can be used to develop primary prevention strategies; and
- Assisting families and their providers in the prevention of secondary disabilities.

The **objectives** of the NBDPN are to:

- Improve the quality of birth defect surveillance data.
- Promote scientific collaboration for the prevention of birth defects.
- Provide technical assistance for the development of uniform methods of data collection.
- Facilitate the communication and dissemination of information related to birth defects.
- Collect, analyze, and disseminate state and population-based birth defect surveillance data.
- Encourage the use of birth defect data for decisions regarding health services planning, including the prevention of secondary disabilities.

¹ The Network Bylaws are viewable at: <http://www.nbdpn.org/bylaws.html>

NETWORK ORGANIZATION AND GOVERNANCE

The Network currently is composed of two classes of members. “Participating Members” include individuals from states or other types of organizations with an interest in and a commitment to the NBDPN mission. There are approximately 250 such participating members. These participating members include 7 organizations that participate as affiliates; they have designated liaisons who foster communication between the Network and their organizations. “Associate Members” include designated representatives of organizations with national interests; currently, there are two associate members from the March of Dimes and the Centers for Disease Control and Prevention. They are appointed by the Executive Committee and are ineligible to hold an elected position with the Network.

MEMBERSHIP

Applications to become a member of the Network should be submitted to the Membership and Elections committee through the Network website at <http://www.nbdpn.org> and select the “How to Join” link. The Membership and Elections Committee sends membership renewal notices to members every two years. Currently, the Network has no dues; however, dues may be levied in future years.

MEETINGS

The Bylaws require an annual meeting of members. In past years these meetings have been in-person, with attendance ranging from 200-250. If the costs become prohibitive for meeting face-to-face, some future meetings may be held electronically (e.g., telephone conference or videoconference).

OFFICERS AND ELECTED MEMBERS

There are four Network officers: President, President-Elect, Secretary-Treasurer, and Immediate Past President. The terms of office run from January 1 until December 31 each year. The Member-at-large also is an elected position. The duties of these positions are described in the Bylaws.

BUSINESS FUNCTIONS

An Executive Committee (EC) manages the business details of the Network. The EC is comprised of the four officers, the member-at-large, chairpersons from eight standing committees, and the two Associate Members. Meetings of the Executive Committee must occur at least four times per year. The EC is responsible for conducting the affairs of the corporation, approving its budget, and entering into contracts. The EC also provides general direction for the standing committees.

NETWORK ACTIVITIES

Standing committees carry out most of the work and activities of the Network. The standing committees produce tangible products and information of use to members. All NBDPN members are encouraged to serve on one of these committees and to participate in their activities. The chairperson of each standing committee also serves on the Executive Committee. The list of current chairpersons and their contact information is provided on the NBDPN website and on the back of the NBDPN biannual newsletter.

The eight **Standing Committees** of the Network are:

1. Annual Meeting
2. Data
3. Education and Outreach
4. Ethical, Legal, and Social Issues
5. Membership and Elections
6. Neural Tube Defect Surveillance and Folic Acid Education
7. Publications and Communications
8. Surveillance Guidelines and Standards

WHAT CAN YOU DO?

- 1) Join the Birth Defects Listserv
 - a) To join the listserv, send the following e-mail:
To: listserv@listserv.cdc.gov
Subject: (leave blank)
Message: subscribe birth-defects-surv
 - b) If successful, you will get an e-mail reply saying that you are subscribed with further details and instructions for use. When you send messages to the listserv, it's a good idea to receive confirmation of your messages. To have the entire message sent back to you whenever you send a message, send the following e-mail (only need to send this once, after you join the listserv, not every time you send a message):
To: listserv@listserv.cdc.gov
Subject: (leave blank)
Message: set birth-defects-surv repro
 - c) If you encounter any problems, please contact Cara Mai at cmai@cdc.gov or 404-498-3918.
- 2) Visit the NBDPN website at <http://www.nbdpn.org>
 - a) Check your membership status and keep your address current:
 - b) Explore various other links and pages of our website
- 3) Join a standing committee--it's easy. Simply sign-up on a committee's membership sheet at the NBDPN registration desk or send an email to the committee chair.