

NBDPN Annual Business Report 2012

Mission

The National Birth Defects Prevention Network (NBDPN) is a group of individuals involved in birth defects surveillance, research, and prevention. It was created to establish and maintain a national network of state and population-based programs for birth defects surveillance and research. The Network assesses the impact of birth defects upon children, families, and health care; identifies factors that can be used to develop primary prevention strategies; and assists families and their providers in secondary disabilities prevention.

Goals

- **Improve access** and application of information about the prevalence and trends of birth defects
- **Increase collaboration** between members within the birth defects community
- **Advance science** through birth defects surveillance and its application to public health efforts and resource allocation

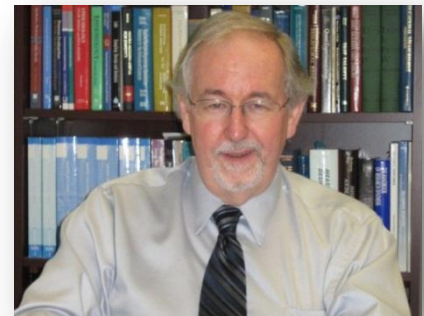


CONTENTS

Mission	1
Goals	1
From the President	2
NBDPN Management	3
2012 NBDPN Officers	3
NBDPN Strategic Plan	4
Background	4
Goals	4
NBDPN 15 th Annual Meeting	5
Awards	5
Highlights 2012	7
Birth Defects Prevention Month	7
Surveillance Standards and Guidelines	7
NBDPN Member Organizations 2012	8
Membership	8
NBDPN Partners	9
Parent Advisory Group	9
NBDPN, Inc. Financial Report 2011	10
Revenues & Expenses	10
Fiscal Snapshot 2012 and 2013 Proposed Budget	11
2012 Projected Revenues & Expenses (as of 9-30-2012)	11
2013 Proposed Budget	11
Acknowledgements	12

From the President

The NBDPN has been instrumental in developing birth defects registry standards that establish core requirements for effective surveillance efforts and promote uniformity across state and regional registries. The Network has also facilitated a number of multistate research efforts that enable addressing research which would be impractical without cross-registry collaboration.



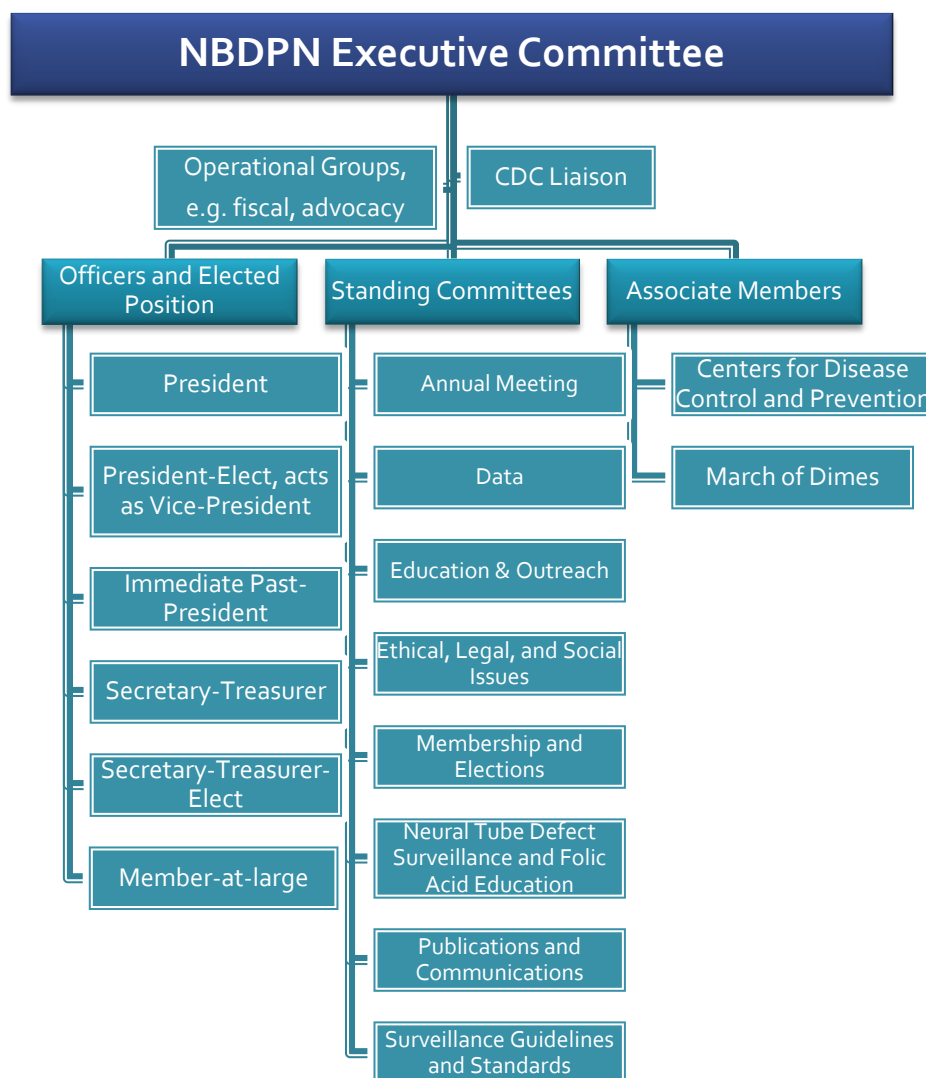
Three key products of which we are especially proud are the Annual Report on birth defects prevalence published in a special issue of Birth Defects Research Part A, the annual Birth Defects Prevention Month template that provides focused and informative materials on specific birth defects prevention topics and the NBDPN Birth Defects Surveillance Guidelines.

- David Law, 2012 NBDPN President



NBDPN Management

An Executive Committee serves as the organization's board of directors and comprises elected officers, elected positions, standing committee chairs, selected Associate members, and an appointed representative who serves as the administrative liaison from the Centers for Disease Control and Prevention. Although not on the board, other operational groups in the organization provide technical and consultative support to the Executive Committee. The Standing Committees develop core products and implement many of the NBDPN activities.



2012 NBDPN Officers

David Law (TN),
President

Leslie Beres (NJ),
President-Elect

Glenn Copeland (MI),
Past-President

Joan Ehrhardt (MI),
Secretary-Treasurer

Craig Mason (ME),
Secretary-Treasurer
Elect

Sandy Fawbush (KY),
Member At-large



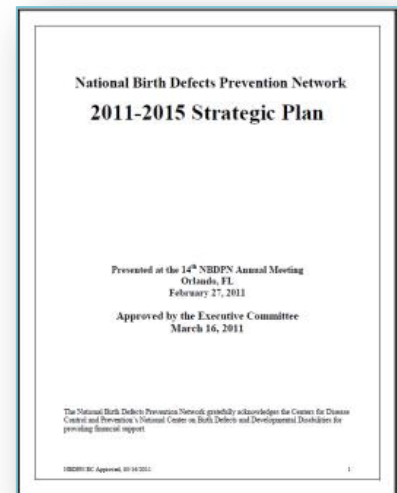
NBDPN Strategic Plan

2011-2015

Background

The National Birth Defects Prevention Network, a membership organization founded in 1997, became a 501 (c) (3) nonprofit organization in September of 2000. The Network's leadership developed the original strategic plan in 2005. The revision process began with a team of eighteen Steering and Advisory group members, a CDC Liaison, and a professional nonprofit facilitator.

Strategic planning took into consideration the results of the prior five year plan; the knowledge and experience of NBDPN leadership and key stakeholders; and the internal and external environment. An environmental scan was conducted with the help of PRQuickhelp Consulting, administrative support from the Centers for Disease Control and Prevention, and other strategic planning group members.



Goals

Goal I: Establish and support activities, services, and products that help the Network accomplish its mission

Goal II: Establish new partnerships and strengthen existing collaborations that increase the effectiveness of the Network.

Goal III: Create and maintain the optimal infrastructure to support the mission of the Network.

Goal IV: Create a diversified funding base to support infrastructure and core program services.

NBDPN 15th Annual Meeting

Birth defects registries, prevention partners and others interested in the wellbeing of individuals with birth defects come together for education and networking at the Annual Meeting. In addition to key note presentations and workshops, NBDPN committees, workgroups and partners take the opportunity to meet face-to-face.

The Network promotes and celebrates member achievements during the meeting through a juried poster session and award ceremony.

The Social Event provides casual time to meet other members. Members enjoy taking part in friendly competition during the Silent Auction, while giving to the organization.



Awards

The Network acknowledges the stunning achievements of individuals, programs, and agencies. The Awards Presentation is a shining moment for NBDPN members and others working in the field of birth defects.

GODFREY P. OAKLEY, JR. AWARD

Since 2001, NBDPN has presented this prestigious award in Dr. Oakley's honor to an individual who has made significant contributions to the field of birth defects.

2012 Recipient: **Lewis B. Holmes, MD**



STATE LEADERSHIP AWARD

This award honors an outstanding contribution (or leadership) by a state birth defects program.

2012 Recipient: **Florida Birth Defects Registry**



BIRTH DEFECTS EDUCATION & PREVENTION AWARD

This award is given honoring an agency's or birth defects program's efforts to raise public awareness of birth defects through innovative and collaborative projects.

2012 Recipients:

Arkansas Children's Hospital Research Institute and University of Arkansas for Medical Sciences

Michigan Department of Community Health and Ohio Department of Health

NBDPN PRESIDENT'S AWARD

This award honors an NBDPN member who has made significant contributions important to the mission and goals of the National Birth Defects Prevention Network, Inc.

2012 Recipient: **Ann F. Phelps (TX)**



NBDPN DISTINGUISHED SERVICE AWARD

This award honors an NBDPN member who has provided significant time and effort over many years in support of the mission and goals of the National Birth Defects Prevention Network, Inc.

2012 Award Recipients:

Melanie Lockhart (DC) and

Angela Lin (MA)



Highlights 2012

Birth Defects Prevention Month

And the beat goes on....

...looking to the future for healthy hearts

Each year, the National Birth Defects Prevention Network prepares a template of materials, working with healthcare professionals and public health agencies around the country to encourage prevention and awareness. In 2012, the focus was congenital heart defects.

Congenital heart defects include abnormalities of the heart that are present at birth. Some have only a minor and brief effect on a baby's health and some have very serious and life-long effects. Nearly 40,000 cases (approximately 1 in 110 live births) are reported annually in the US. Public awareness, accurate diagnosis, and expert medical care are all essential for adequate prevention and management of these all too common and deadly conditions.



Surveillance Standards and Guidelines

The Network established the Surveillance Guidelines and Standards Committee (SGSC) in order to develop standards and guidelines for birth defects surveillance and promote their use by programs nationally. The *NBDPN Guidelines for Conducting Birth Defects Surveillance* were published in 2004 with the overarching long-term objectives of:

- Improving the quality of data (accuracy, comparability, completeness, and timeliness)
- Enhancing the utility of data for research on the distribution and etiology of birth defects
- Promoting the use of data for linking affected children with services and for evaluation of access to services

Birth defect surveillance standards are a priority for the NBDPN and development has been assigned to the SGSC. Standards will:

- Demonstrate the unique value of these surveillance systems to generate quality data on birth defects
- Help states advocate for additional resources to improve their systems



- Produce better national estimates and meaningful comparisons across regions
- Facilitate state collaborations
- Prepare surveillance systems for the future (e.g., electronic health records and ICD-10)

To address this priority, the SGSC formed a Birth Defects Standards Steering Committee to develop draft standards. The draft standards have two components (data quality and data utilization). Data quality represents the foundation of our programs and data utility demonstrates the value of birth defects surveillance systems. The committee has developed an assessment tool structure that state programs can use to assess their performance against the standards. After additional refinement and pilot testing, the SGSC will integrate these standards into the Birth Defects Surveillance Guidelines document thus producing one cohesive document that includes both standards and guidelines.

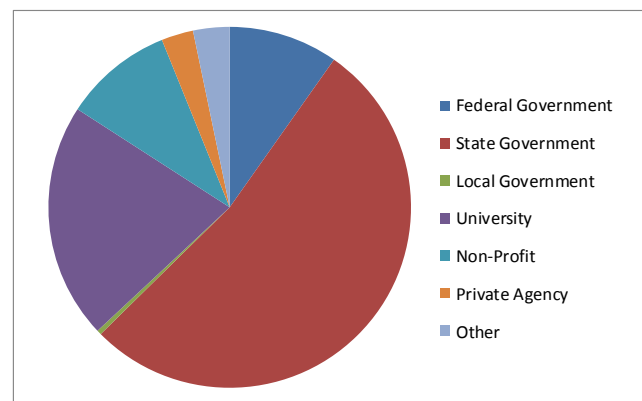
NBDPN Member Organizations 2012

Membership

The Network implemented membership dues for the first time in 2011. The membership year runs from July 1st to June 30th. NBDPN members come from diverse organizations, with just over half representing state public health.

ANNUAL MEMBERSHIP DRIVE

During 2012 the Network exceeded its membership goal of 200 paid members.



CATEGORY	NUMBER	REVENUE	%	DESCRIPTION
Annual Meeting Registration	173	\$ 8,650.00	73%	Complimentary
Summer Membership Drive	54	\$ 2,700.00	23%	New and renewing
Lifetime Member	10	\$ -	4%	Godfrey Oakley Award
Individual Member Request	1	\$ 50.00	<1%	Join request via website
TOTAL	238	\$ 11,400.00	100%	114% of goal



NBDPN Partners

The NBDPN has established relationships with many organizations which have a compatible mission. The Centers for Disease Control and Prevention (CDC) and the March of Dimes Foundation (MOD) are NBDPN associate members. As such, they are represented on the Networks' Executive Committee. These associates play a crucial role in developing and advancing Network objectives. NBDPN collaborated with various partners on key activities in 2012.

The American Academy of Pediatrics worked closely with the NBDPN on several initiatives including: joint webinars focused on birth defects; development, dissemination and promotion of Birth Defects Prevention Month materials; education of providers on critical congenital heart defect (CCHD) screening; and development of strategies to increase awareness and promote folic acid use for neural tube defect (NTD) recurrence prevention.

The MOD, the Association of Maternal and Child Health Programs (AMCHP), the Network and others developed communication materials to be used for advocacy efforts regarding legislative funding and appropriations.

The Teratology Society, which publishes the NBDPN Annual Report in Birth Defects Research-Part A, played a critical role in disseminating prevention information in their special issue published in December 2012.

Parent Advisory Group

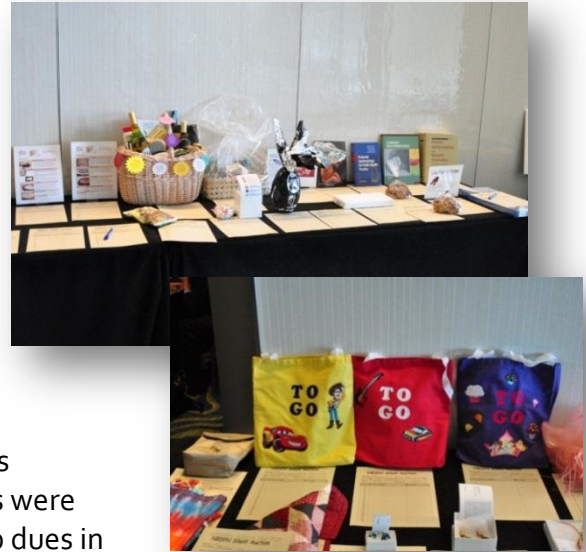
Parents of children with various conditions participate, providing insight and guidance regarding family and individual needs and the relevance of Network activities. In 2012, this group worked closely with the Utah Birth Defect Network, CDC, and NBDPN to develop the Network family extension website at endbirthdefects.org, debuting in January 2013.



NBDPN, Inc. Financial Report 2011

NBDPN, Inc. is a 501(c)3 non-profit organization that is incorporated in Delaware. NBDPN, Inc. is an all-volunteer organization without a centralized office. Operations are distributed among volunteer members nationally.

In the 2011 fiscal year (Jan-Dec), NBDPN received 73% of its revenue from the Annual Meeting and 87% of the expenses were related to the Annual Meeting. Revenue from membership dues in 2011, the first year of paid membership, was 9%.

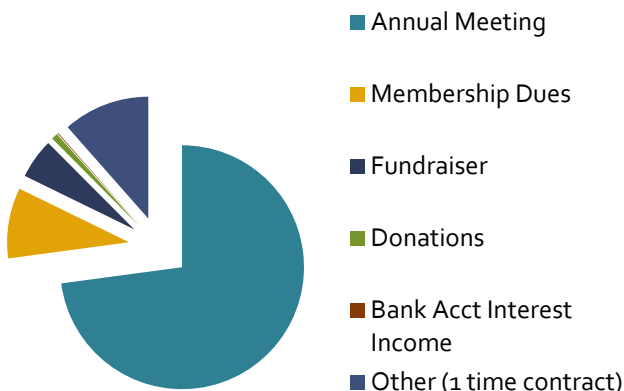


Revenues & Expenses

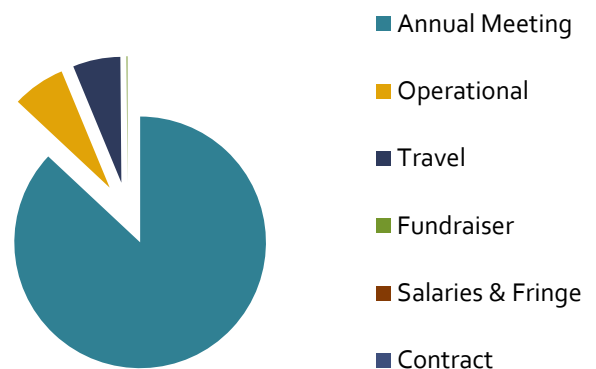
Revenues		% Total
Annual Meeting	\$47,500.00	73%
Membership Dues	\$6,100.00	9%
Fundraiser	\$3,453.69	5%
Donations	\$557.00	<1%
Bank Acct. Interest Income	\$70.74	<1%
Contract	\$7,500.00	12%
Total Annual Revenues	\$65,186.73	100%

Expenses		% Total
Annual Meeting	\$39,682.00	87%
Operational	\$3,099.86	7%
Travel	\$2,791.31	6%
Fundraiser	\$57.11	<1%
Salaries & Fringe	\$0.00	0%
Contract	\$0.00	0%
Total Annual Expenditures	\$45,630.73	100%

2011 Revenues



2011 Expenses



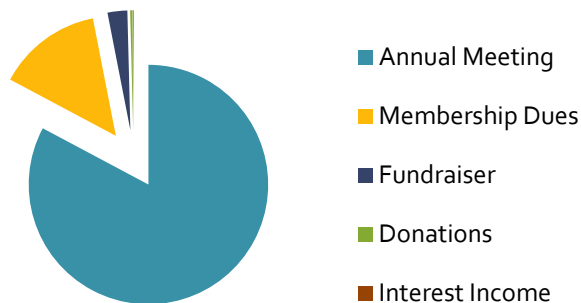


Fiscal Snapshot 2012 and 2013 Proposed Budget

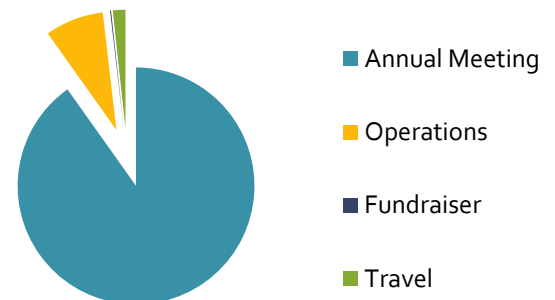
2012 Projected Revenues & Expenses (as of 9-30-2012)

Revenues			Expenses		
		% Total			% Total
Annual Meeting	\$66,735.00	83%	Annual Meeting	\$69,125.32	90%
Membership Dues	\$11,400.00	14%	Operational	\$6,125.74	8%
Fundraiser	\$2,149.73	3%	Travel	\$1,313.61	2%
Donations	\$260.00	<1%	Fundraiser	\$100.00	<1%
Bank Acct. Interest Income	\$67.76	<1%	Salaries & Fringe	\$0.00	0%
Total Annual Revenues	\$80,612.50	100%	Total Annual Expenditures	\$76,664.67	100%

2012 Revenues



2012 Expenses



2013 Proposed Budget

Revenues			Expenses		
		% Total			% Total
Annual Meeting	\$63,450.00	83%	Annual Meeting	\$60,350.00	81%
Membership Dues	\$10,000.00	13%	Operational	\$8,721.00	12%
Fundraiser	\$2,000.00	3%	Travel	\$5,500.00	7%
Donations	\$500.00	<1%	Fundraiser	\$100.00	<1%
Bank Acct. Interest Income	\$80.00	<1%	Salaries & Fringe	\$0.00	0%
Total Annual Revenues	\$76,030.00	100%	Total Annual Expenditures	\$74,671.00	100%



Acknowledgements

The National Birth Defects Prevention Network would like to acknowledge the hard work and dedication of its members, partners and benefactors.

The many accomplishments of 2012 were made possible through their contribution to standing committees, workgroups, and special events.

National Birth Defects Prevention Network (NBDPN)
14781 Memorial Drive, #1561, Houston, TX 77079

Email: NBDPN@NBDPN.org Website: <http://www.NBDPN.org>
