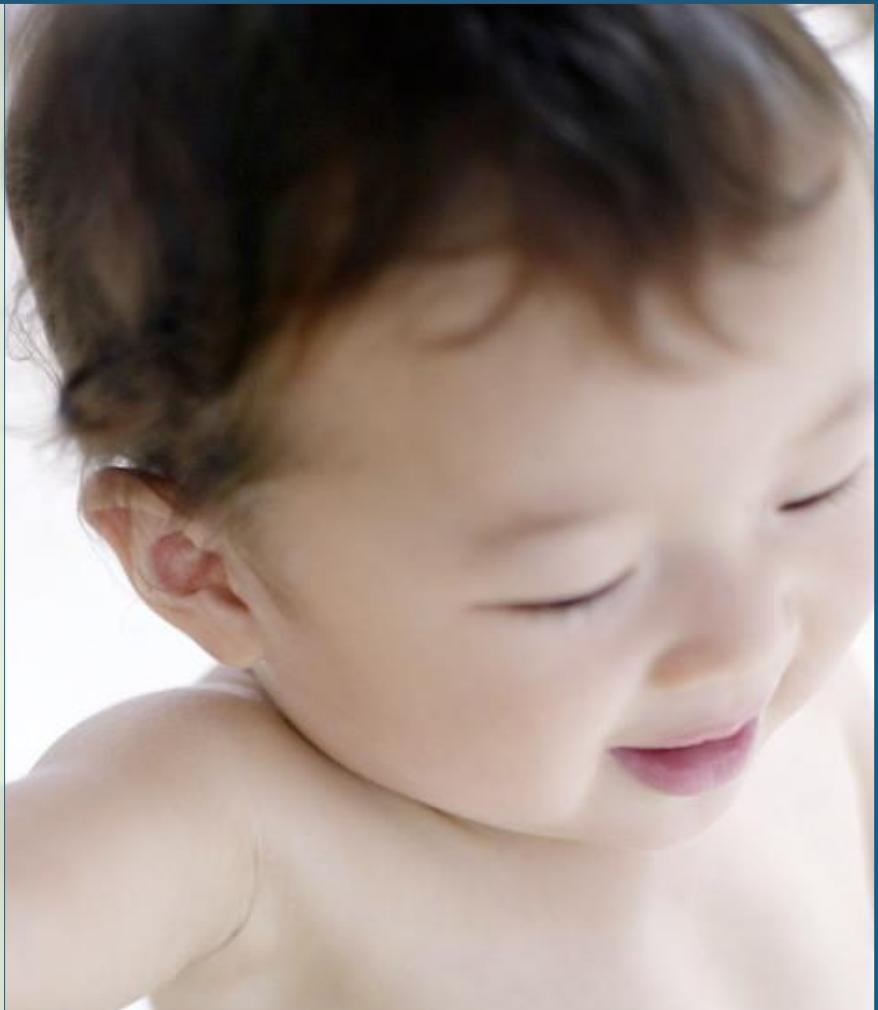


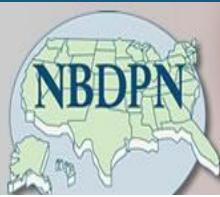
January is

National Birth Defects Prevention Month

2014



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National Birth Defects Prevention Network

Birth Defects Surveillance, Research & Prevention

GREETINGS

It is with great pleasure that we provide you with the materials for the 2014 National Birth Defects Prevention Month, developed by the National Birth Defects Prevention Network's Education and Outreach Committee.

National Birth Defects Prevention Month involves the efforts of many organizations. Building on our theme from last year, "Every 4 ½ minutes a baby is born with a birth defect," NBDPN's goal for 2014 is to continue to increase awareness that birth defects are "Common, Costly and Critical" and to offer actionable steps that can be taken by professionals, community groups, and the public to prevent birth defects. Birth defects affect 1 in every 33 babies born in the United States and are a leading cause of infant mortality. Babies who survive and live with birth defects are at increased risk for developing many lifelong physical, cognitive, and social challenges. Medical care and support services only scrape the surface of the financial and emotional impact of living with birth defects.

Awareness efforts offer hope for reducing the number of birth defects in the future. The following prevention strategies can be promoted. Please encourage all pregnant women and those who may become pregnant to:

- Consume 400 micrograms of folic acid daily
- Manage chronic maternal illnesses such as diabetes, seizure disorders, or phenylketonuria (PKU)
- Reach and maintain a healthy weight
- Talk to a health care provider about taking any medications, both prescription and over-the-counter
- Avoid alcohol, smoking, and illicit drugs
- See a health care provider regularly
- Avoid toxic substances at work or at home
- Ensure protection against domestic violence
- Know their family history and seek reproductive genetic counseling, if appropriate

Please take the time to become familiar with the materials and complete the [Evaluation Form](https://www.surveymonkey.com/s/3FV7D9W) (<https://www.surveymonkey.com/s/3FV7D9W>). We hope you find them useful for the education, outreach, and prevention activities that you conduct in your community. Materials developed by NBDPN are available on the NBDPN website and can be tailored to your specific agency's mission, needs, and capacity. Materials from the other organizations featured can be obtained directly from the organizations themselves.

If you should have questions about Birth Defects Prevention Month, please contact Mary Knapp (Mary.Knapp@doh.state.nj.us) or Cara Mai (cmai@cdc.gov). We hope you find these materials helpful in providing information about birth defects to families, colleagues, and policy makers. *Thank you in advance for your support in promoting January as National Birth Defects Prevention Month.*

Sincerely,
Mary Knapp and LaShunda Williams
NBDPN Education & Outreach Committee Co-chairs



Common

Costly

Critical

SHARING THE ENTIRE PACKET

Materials in this packet can be downloaded from the NBDPN website, www.nbdpn.org. All materials can be printed, electronically conveyed, or added to websites for distribution as needed. Copies of brochures can be requested from their creators and most are available at no cost. Here are a few suggestions for packet dissemination:

- Health educators and school nurses at middle schools, high schools, colleges, and universities in your state can share materials with teachers and students. School health education teachers can incorporate the information into their lesson plans. Professors at Schools of Nursing at both the undergraduate and graduate levels might want to include information in their curricula.
- March of Dimes chapters: health care advocates like the Healthy Mothers, Healthy Babies Coalitions; Family Voices and family support groups can promote information to policy makers.
- Your state's chapter of professional organizations, such as the American Medical Association, American Academy of Family Practice, American Academy of Pediatrics, American College of Obstetricians and Gynecologists, American Public Health Association, National Association of Community Health Centers, nursing organizations, and genetic associations can share up-to-date materials through their meetings, newsletters, and conferences.
- Contact and share the information packet with your state's Maternal and Child Health (MCH), Children's Special Health Care Services (CSHCS), Reproductive Health, Family Planning, Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) and Medicaid programs. Offer them enough packets to distribute to each of their offices around the state. The Fetal and Infant Mortality Review Program (FIMR) in your state may be interested in prevalence and mortality statistics and prevention resources.
- If your state has local public health departments, share the packet with each department.
- If your state has a Women's Commission, contact a representative or your agency's liaison and tell them about the work of the NBDPN and National Birth Defects Prevention Month so they can let interested members know.
- Your state's Health and Hospital Association and health care provider organizations may be interested in issues surrounding birth defects, and in helping spread prevention messages to their providers.
- Remember to reach young women. Child and Adolescent Health Centers (CAHC), school-based health centers, and family planning clinics can incorporate prevention messages into their programs.



USING MATERIALS IN THIS PACKET

Individual activities and those conducted with partners at the state or community level will raise awareness about what can be done to promote healthy pregnancies and positive birth outcomes.

- Contact state or local businesses. Companies may post information about birth defects awareness and prevention to their Facebook pages and Twitter feeds, sponsor events such as baby fairs, or donate door prizes such as folic acid rich food baskets to bridal fairs, health fairs, and other community events.
- Share the important prevention messages and resources in the packet with staff at your state's Chronic Disease Prevention and Control, Tobacco Control, Refugee and Immigrant Health, and Public Health Nursing Programs. Other state level programs that serve women of childbearing age such as home visiting may also be interested. They may have ideas for distribution to local public health and other community partners.
- Ask local food banks, women's shelters, Head Start programs and other similar services to provide information to their clients.
- Ask community colleges and universities to place materials in their health center waiting rooms. Information about birth defects, alcohol consumption, smoking cessation and the importance of folic acid is especially relevant given the fact that about 50% of pregnancies are unplanned
- Supply pamphlets or fact sheets for patients and professionals to health care provider groups, such as managed care organizations, doctors' offices, HMOs, and clinics, especially Federally Qualified Health Clinics.
- Collaborate with hospitals or clinics on community outreach projects to promote an awareness of birth defects and prevention. Topics could include preconception counseling and healthy lifestyles.
- Volunteer to present information on birth defects and birth defects prevention to professional groups such as nurses, nutritionists, or genetic counselors, as well as community health workers and health advocacy groups.
- Connect with supportive partners in the media. Prepare public service announcement scripts and write educational articles that may be used or adapted by local media. Recruit a "birth defects prevention champion" for media interviews.
- Parents, grandparents, and/or community members can incorporate birth defects awareness at the next family gathering or community event. Ask questions about birth defects, and then offer a prize to the person who answers each question correctly. See [10 Things To Know About Birth Defects](#) for question ideas.
- Contact the Communications lead for your agency. Ask that Birth Defects Prevention Month and the packet be announced in the agency newsletter, or in an "ALL" email.



SAMPLE PROCLAMATION

The nation's most precious resource is our children, and birth defects are a leading cause of death in the first year of life. Birth defects are devastating to families and communities.

- Whereas, Every 4 ½ minutes a baby is born in the United States with a birth defect. Birth defects cause one in every five infant deaths and lead to \$2.6 billion per year in hospital costs alone in the United States. In **(name of your state)**, birth defects account for about ### infant deaths every year; and
- Whereas, Birth defects can occur in any family regardless of race, health history, economic status, or level of education; and
- Whereas, About half of all pregnancies are unplanned, contributing to late entry into prenatal care and presenting a barrier to optimal pregnancy management, particularly during the crucial early weeks of embryonic development; and
- Whereas, Early identification of a child with a birth defect coupled with early intervention services typically improves the child's quality of life and may even save his or her life; and
- Whereas, Strategies to prevent birth defects include taking a multivitamin with folic acid daily to prevent serious defects, maintaining a healthy weight, having regular checkups, avoiding alcohol and tobacco use during pregnancy, learning about family history and genetic risks, and managing maternal medical conditions while minimizing unnecessary medication exposure in pregnancy; and
- Whereas, The good health and well-being of the people of **(name of your state)** are enhanced by the support of a national effort to educate about and prevent birth defects; and
- Whereas, The **(name of your state Department of Public Health)** and the **(name of your state Birth Defects program)** join with the March of Dimes, the American Academy of Pediatrics, the Association of University Centers on Disabilities and the National Birth Defects Prevention Network, as well as many dedicated volunteers, healthcare professionals, and parent groups by participating in this promotion.

NOW, THEREFORE, I, **(Governor's name)**, Governor of the state of **(name of your state)**, do hereby declare the month of January 2014 as National Birth Defects Prevention Month.



SAMPLE NEWS RELEASE

FOR IMMEDIATE RELEASE
January 1, 2014

Contact: (*Name of person submitting release*)
(*Phone here*) – or – (*Email here*)

National Birth Defects Prevention Month Seeks to Raise Awareness of Birth Defects

(*Your City, Your State*) – (*Your organization*) is joining the National Birth Defects Prevention Network (NBDPN) to increase awareness of birth defects, the leading cause of infant mortality in the United States. In fact, every 4 ½ minutes, a baby is born with a birth defect in the United States. In honor of January as *National Birth Defects Prevention Month-2014*, (*your organization*) is actively focusing on raising awareness among healthcare professionals, educators, social service professionals, and many segments of the general public about the frequency with which birth defects occur in the United States and the steps that can be taken to prevent them. The risk for many types of birth defects can be reduced through healthy lifestyle choices and medical care before and during pregnancy.

There are many different kinds of birth defects including congenital heart defects, cleft lip or palate, defects of the brain and spine, bones, muscles and internal organs, and a variety of genetic syndromes such as Down syndrome. Some have only a minor and brief effect on a baby's health while others have life-threatening or life-long effects, which can often be lessened by early detection and treatment.

More than 120,000 babies born with a birth defect (approximately 1 in every 33 live births) are reported each year in the United States with around (*prevalence information for your state from your state's birth defects tracking system or other source*) cases occurring in (*name of your state*). Birth defects are the most common cause of death in infants and the second most common cause of death in children aged one to four years. Public awareness, expert medical care, accurate and early diagnosis, and social support systems are all essential for optimal prevention and treatment of these all-too-common and often deadly conditions.

"Most people are unaware of how common, costly and critical birth defects are in the United States, or that there are simple steps that can be taken to reduce the risk of birth defects." says (*your contact*).

"The health of both parents prior to pregnancy can affect the risk of having a child with a birth defect. Food intake, life-style choices, factors in the environment, health conditions and medications before and during pregnancy all can play a role in reducing or increasing the risk of birth defects," says (*your contact*) of (*your organization*).

Studies have demonstrated several important steps women can take to help prevent birth defects. Women who are pregnant or may become pregnant are advised to:

- Consume 400 micrograms of folic acid daily
- Manage chronic maternal illnesses such as diabetes, seizure disorders, or phenylketonuria (PKU)
- Reach and maintain a healthy weight
- Talk to a health care provider about taking any medications, both prescription and over-the-counter

- Avoid alcohol, smoking, and illicit drugs
- See a health care provider regularly
- Avoid toxic substances at work or at home
- Ensure protection against domestic violence
- Know their family history and seek reproductive genetic counseling, if appropriate

“Small steps like visiting a healthcare provider before pregnancy and taking a multivitamin every day can go a long way,” says (**your contact’s last name**). The NBDPN is working with healthcare professionals and public health agencies around the country to encourage prevention and awareness of birth defects among the over 60 million women of childbearing age in the United States. In addition to its efforts in prevention, the NBDPN works to improve nationwide surveillance of birth defects and to advance research on possible causes. It also offers support to families who are dealing with the realities of a child born with one of these conditions. Further information about the NBDPN can be found at www.NBDPN.org.

(**Your organization**) is participating in National Birth Defects Prevention Month by (*add two details about your local activities, e.g., distributing information to women and their health care providers across the state, participating in health fairs, offering presentations at local schools. etc.*). “We are excited to be part of this national campaign. Through our efforts across the country we plan to reach millions of women and their families with vital prevention information,” says (**your contact’s last name**).

To learn more, please contact (**your organization**) at (**phone here**) or (**E-mail here**).

The 2014 NBDPN Birth Defects Prevention information packet (as well as archives of past packets) is available online at: <http://www.nbdpn.org/bdpm2014.php>. All materials can be printed, electronically conveyed, or added to websites for distribution as needed.



SAMPLE LETTER TO HEALTH CARE PROVIDERS - SHORT VERSION (1)

Dear Medical Professionals and Health Care Providers (*or individual's name*):

January is National Birth Defects Prevention Month – 2014! The National Birth Defects Prevention Network (NBDPN) is offering a resource packet with up-to-date, targeted information for professionals, their patients, and interested members of the general public. (“I”, “we” OR YOUR ORGANIZATION’s NAME) urge you to take part in local and nationwide efforts to raise awareness of birth defects, their causes, and their impact, with the ultimate goal of reducing the incidence of preventable birth defects and their secondary complications through evidence-based methods of prevention, early detection, and treatment.

National Birth Defects Prevention Month involves the efforts of many organizations. Building on our theme from last year, “Every 4.5 minutes a baby is born with a birth defect,” NBDPN’s goal for 2014 is to continue to build awareness that birth defects are “Common, Costly and Critical” and to offer actionable steps that can be taken by professionals, community groups, and the public to prevent birth defects. You are in a position to raise awareness and help your patients to lower their risk of certain birth defects, detect those that do occur as early as possible, and act to prevent secondary complications. Ultimately, these efforts will assure more healthy children, reduce birth defect associated health care as well as personal, societal and emotional costs, and lead to a healthier future for children, families, and society.

As you know, although not all birth defects can be prevented, the healthcare community can help all women, including teens, to lower their risk of having a baby with a birth defect and to avoid other complications of pregnancy by encouraging them to follow some basic health guidelines throughout their reproductive years. Working to make each of your patients of child-bearing age aware of important preventive steps can lead to a reduction in the number of birth defects occurring in your patient population.

(***Enclosed/attached you will find a copy of the packet for your review.***) You can access the packet (as well as archives of past packets) online at: <http://www.nbdpn.org/bdpm2014.php>. All materials can be printed, electronically conveyed, or added to websites for distribution as needed. (*Or contact me/name and info for preprinted copies.*)

You have the power to make a difference. We urge you to join us as an active participant in *National Birth Defects Prevention Month - 2014* and to continue your efforts throughout the year. If (I/we) can help you or your patients further, please feel free to let (me/us) know how. For more information, please contact (me/us) (at _____ (public health/surveillance program/MCH program/Birth Defects/Genetics Program) if applicable) or visit the National Birth Defects Prevention Network at www.nbdpn.org.

Sincerely,
(Your own name if appropriate or your organization)

SAMPLE LETTER TO HEALTH CARE PROVIDERS - LONG VERSION (2)

Dear Medical Professionals and Healthcare providers:

January is National Birth Defects Prevention Month – 2014! The National Birth Defects Prevention Network (NBDPN) Education & Outreach Committee invites you to take part in our efforts to eradicate the preventable causes of debilitating birth defects through integrated healthcare solutions. Our ultimate goal is to educate all participants to decrease the number of birth defects, which will decrease associated healthcare costs, promote healthy children, and create a healthier society.

In (**Your State**), approximately **(###)** babies are born with a defect each year! We ask you to join us to raise public awareness of the prevalence of birth defects and to inform both professional and lay audiences of strategies that can help reduce the risk of birth defects and their complications.

Together we are raising awareness that:

- **Birth defects are common.** In fact, **1 baby is born with a birth defect every 4 ½ minutes**, that is 1 in every 33 babies born each year in the United States [1]. The most common type of birth defect is congenital heart disease, (CHD). CHD has a birth prevalence of about 1 in 100 births [2-4].
- **Birth defects are costly.** In the U.S. each year, the total **hospital costs of children with birth defects exceed \$2.6 billion**. Congenital cardiac and circulatory birth defects account for \$1.4 billion of these annual hospital costs attributed to birth defects [5]. The medical costs, including in-hospital, outpatient, and prescription drug expenses, for a child with an orofacial cleft are 8 times higher than a non-affected child [6]. The medical costs for a child with Down syndrome are 12 to 13 times higher than a child without Down syndrome [7].
- **Birth defects are critical.** About **20% of infant deaths are caused by birth defects** annually in the United States as well as 6-15% of deaths in children up to age 14 years [8-9]. Those that survive and live with birth defects are at increased risk for developing many lifelong physical, cognitive, and social challenges. For example, around 20-30% of patients with CHD have other physical problems or developmental or cognitive disorders [10-11].

It is important to note that none of these numbers consider the loss of income and productivity or the day-to-day emotional and physical stresses that affect both patients and primary caregivers.

Only **30%** of the causes of birth defects are estimated to be known [12], but research continues to further our understanding of the unknown causes. As a result of the research already conducted, many preventive measures have been identified. Raising awareness and achieving universal utilization of these measures, both among the public and the medical profession, can help to significantly decrease the occurrence of birth defects.

Although not all birth defects can be prevented, the healthcare community can help all women, including teens, who are pregnant or could become pregnant to lower their risk of having a baby with a birth defect by encouraging them to follow some basic health guidelines throughout their reproductive years, including:

- ✓ Get a medical checkup before pregnancy and address specific health issues including weight control, diabetes control, and discuss any medications, both over the counter and prescription.
- ✓ Plan carefully. Use contraception if taking medications that increase the risk for birth defects.
- ✓ Take 400 micrograms of folic acid daily from the beginning of menstruation through menopause.
- ✓ Eat a healthy diet and work to maintain a healthy weight.

- ✓ Keep diabetes under control.
- ✓ Avoid tobacco smoke, including second-hand smoke.
- ✓ Stop drinking alcohol prior to pregnancy and during pregnancy. If pregnant, stop drinking as soon as possible. It's not worth the risk.
- ✓ Don't use illegal drugs. (Cannabis, if legalized, should also be avoided.)

You have the power to make a difference. We urge you to join us as an active participant in *National Birth Defects Prevention Month - 2014* and to continue your efforts throughout the year. If (*I/we*) can help you or your patients further, please feel free to let (*me/us*) know how. For more information, please contact (*me/us*) at _____ (**public health/ surveillance program/MCH program/Birth Defects/Genetics Program**) if applicable or visit the National Birth Defects Prevention Network at www.nbdpn.org.

Sincerely,

(Your State) Public Health Service

References:

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8. Matthews TJ, MacDorman MF. Infant mortality statistics from the 2008 period linked birth/infant death data set. National Vital Statistics Reports; vol 60 no 5. Hyattsville, MD: National Center for Health Statistics. 2012.
9. Yang Q., Chen H., Correa A., Devine O., Mathews T. and Honein M.A. Racial differences in infant mortality attributable to birth defects in the United States, 1989–2002. Birth Defects Research Part A: Clinical and Molecular Teratology, 2006;76: 706–713.
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12. Nelson K, Holmes LB. 1989. Malformations due to presumed spontaneous mutations in newborn infants. New England Journal of Medicine 320:19-23.

FACTSHEET FOR POLICY MAKERS

Fact sheet

Use
NBDPN
or your
logo
here

Birth Defects Tracking, Research & Prevention



Tracking where and when birth defects occur and who they affect, is the first step in preventing them. States play a vital role in preventing birth defects by maintaining birth defects tracking programs.

<STATE> BIRTH DEFECTS TRACKING SYSTEM

<Give specific information about your program>.

Since <YEAR>, The <**BIRTH DEFECT TRACKING PROGRAM (BDTP)**> has monitored the prevalence of birth defects in <STATE>. The <BDTP> is a statewide, population-based surveillance program with information on approximately <STATE SPECIFIC NUMBER> infants born with specific birth defects. The <BDTP> was established to identify and describe the patterns and trends of birth defects in <STATE>, provide education and outreach, investigate possible causes, and respond to community concerns about possible clusters of birth defects.

IMPACT OF BIRTH DEFECTS DATA IN <STATE>

The <BDTP> has monitored over <#####> births each year. Data has been collected on over <#####> children born in <STATE> with major structural birth defects. These data are used to detect and respond to reported birth defect clusters in <STATE>, identify potential risk factors, plan, establish, and evaluate primary prevention activities, and identify potential participants for specific birth defect studies. The <BDTP> also provides information to concerned parents and their healthcare providers regarding their child's birth defect.

IDENTIFICATION OF BIRTH DEFECTS NATIONWIDE

There are over 40 birth defects tracking programs in the United States. These programs track babies with birth defects and use the data collected for prevention and referral activities.

Birth defects tracking systems are vital for monitoring and detecting trends, providing information to find causes of birth defects, and planning and measuring the effects of activities aimed at preventing birth defects. Also, identifying birth defects at a state level strengthens public health officials' ability to estimate prevalence and evaluate risk factors that are most important in their community.

IMPORTANCE OF BIRTH DEFECTS TRACKING AND RESEARCH

The value of birth defects tracking programs on clinical and public health research cannot be overstated, as this work has revolutionized the way scientists, clinicians, and health care professionals approach, treat, and manage infants affected by birth defects. This research advances our understanding of preventive measures as well as the needed planning and implementation of health and education services for families of children with special needs.

Birth defects affect us all.

What effect will you have on birth defects?

FACTS ABOUT BIRTH DEFECTS

COMMON

- One in 33 U.S. babies is born with a major birth defect each year.
- [insert STATE numbers]

COSTLY

- The yearly hospital costs for birth defects exceed \$2.6 billion.

CRITICAL

- 1 in 5 infant deaths is due to birth defects, making them a leading cause of infant mortality.

RESOURCES FOR GRANDPARENTS OF A GRANDCHILD WITH A BIRTH DEFECT

New grandparents often feel joy and elation at the thought of their first grandchild. What a special gift! When a grandchild is diagnosed with a birth defect, however, these feelings can sometimes be mixed with fear and anxiety. Learning how to help care for your grandchild with special health needs as well as knowing how to support his or her parents can be a challenge. Below are some tips and resources to help.

Tips:

- Learn about your grandchild's birth defect diagnosis. A number of resources are available on the internet, from your state health department, or birth defect-specific groups. Attending seminars or special talks can also help you learn about the condition.
- Connect with other grandparents and families in your area to listen to their experiences and learn about helpful local resources.
- Ask the child's parents what you can do to help. Listen to them.
 - Be open about your feelings, encouraging them to share their own feelings of fear or joy. Be supportive and comforting. This is a new world for both of you. Offer unconditional love.
 - Offer practical help, like helping with the cooking or doing the laundry. Even offering assistance with the doctor visits can help. If parents say they don't need help at that moment, let them know that the door is open and they can always ask in the future.
 - Avoid judgment. Offer opinions only when asked. Do your best to let the child's parents know they are doing a good job. Respect the decisions they make for their child.



"Nobody can do for little children what grandparents do. Grandparents sort of sprinkle stardust over the lives of little children."

-Alex Haley, American writer

Tips continued:

- If you have other grandchildren, remember to give them attention. Call them or plan special days with them. Try to make sure they don't get lost in the shuffle.
- Take care of yourself. As a grandparent, you want to give of yourself and be supportive, but it's important for you to also take care of yourself so you can better care for your family.

For more information and tips, visit these easily accessible online resources:

- Factsheet on being a grandparent to a child with a heart defect:
<http://www.chfed.org.uk/documents/2013/06/being-a-grandparent-to-a-heart-child-factsheet.pdf>
- Toolkit of resources for grandparents to a child with Down syndrome:
http://www.dsagc.com/documents/Grandparent_Packet.pdf
- Pamphlet of resources for grandparents to a child with Down syndrome:
<http://www.dsacc.org/downloads/parents/agrandparentsguide.pdf>
- March of Dimes: Grandparents and the NICU
<http://www.marchofdimes.com/baby/grandparents-and-the-nicu.aspx>
- ParentingSquad.com: Be the Best Grandparent To a Child With Special Needs
<http://parentingsquad.com/be-the-best-grandparent-to-a-child-with-special-needs>
- Grandparenting a child with a disability: An emotional rollercoaster
Woodbridge S, Buys L, Mille E. Australas J Ageing. 2009;28(1):37-40.
<http://onlinelibrary.wiley.com/doi/10.1111/j.1741-6612.2008.00344.x/pdf>
- National Birth Defects Prevention Network:
http://www.nbdpn.org/state_programs_and_related_lis.php



INTERNET RESOURCES

The information and resources listed are intended for educational use only and are provided solely as a service. The information provided should not be used for diagnosing or treating a health problem or disease, and is not a substitute for professional care. These links do not constitute an endorsement of these organizations or their programs by the National Birth Defects Prevention Network (NBDPN) and none should be inferred. The NBDPN is not responsible for the content of the individual organization web pages found at these links.

GENERAL BIRTH DEFECTS & BIRTH DEFECTS DATA

Centers for Disease Control and Prevention (CDC) – Birth Defects (www.cdc.gov/ncbddd/birthdefects)

This website provides information on birth defects in general. Sub-pages provide resources documenting the public health burden of birth defects and their complications in the United States. Statistics on the occurrence of some of the more common birth defects and links to additional information and resources can also be found here.

Centers for Disease Control and Prevention (CDC) / National Center on Birth Defects and Developmental Disabilities (www.cdc.gov/ncbddd/)

This website provides information on preconception, pregnancy, birth defects, and developmental disabilities as well as CDC's activities related to each of these topics. The site includes relevant publications, health topics A-Z, and links to the CDC home page.

March of Dimes (MOD) Foundation (www.marchofdimes.com)

This site contains a wealth of information about the March of Dimes, birth defects, and infant health statistics. There are also additional links to other sources of birth defects data (www.marchofdimes.com/baby/birthdefects.html).

National Institutes of Health - Birth Defects (www.health.nih.gov/topic/BirthDefects)

This website provides updates on the latest health and scientific research conducted by NIH. The "Health Information Index" has a subject/word guide to diseases and conditions under investigation at NIH. This site also provides access to online catalogs, journals, and grant funding information. The Birth Defects page (<http://www.nichd.nih.gov/health/topics/birthdefects/Pages/default.aspx>) provides links to various related organizations and resources.

Organization for Teratology Information Services (OTIS) (<http://www.mothertobaby.org/>)

MotherToBaby, a service of the non-profit Organization of Teratology Information Specialists, offers information about exposures to possible harmful substances during pregnancy. It contains a list of state contacts for teratology information, fact sheets on specific exposures, special projects, and links.

Teratology Society (www.teratology.org)

The Teratology Society website provides information on teratogens (factors or agents that adversely affect the developing baby), membership information, and links to numerous birth defects sites. It also features a teratology discussion forum.

FAMILY SUPPORT AND ADVOCACY ORGANIZATIONS

The Arc of the United States (www.thearc.org)

The Arc is the largest national community-based organization advocating for and serving people with intellectual and developmental disabilities and their families. They encompass all ages and all spectrums from autism, Down syndrome, Fragile X and various other developmental disabilities. This site has many resources available and has a directory of state chapters.

HealthyChildren.Org (www.healthychildren.org)

This parenting website is sponsored by the American Academy of Pediatrics. It contains general information related to child health as well as more specific guidance on parenting issues. Information regarding the American Academy of Pediatrics' many programs and activities can also be found here.

Institute for Child Health Policy (www.ichp.ufl.edu/)

The Institute for Child Health Policy focuses its attention on children in managed care with special emphasis on children with special health care needs. Issues of access, utilization, cost, quality, and family involvement are principal areas of interest for the policy/program development, health services research, and evaluation programs. This website also has a number of videos to assist families to talk to doctors and help with transition from pediatric to adult care (<http://ichp.ufl.edu/research/videos/>).

Keep Kids Healthy (www.keepkidshealthy.com/inside_pediatrics/family_history.html)

This is a parent-focused site that contains a wealth of resources on family history in relation to diseases. It helps increase awareness of the role family history plays in both risk of disease and the promotion of health.

National Center for Medical Home Implementation (NCMHI) State Resources (www.medicalhomeinfo.org)

The overarching goal of the NCMHI is to ensure that all children and youth, including children with special needs, have a medical home where health care services are accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally competent. The NCMHI State Resources page provides comprehensive information for each state.

Special Child (www.specialchild.com)

This website is dedicated to providing support and information to parents and caregivers of children with special needs. This site includes family issues, success stories, and useful information for parents and caregivers, including a section on tips for caregivers.

Surgeon General's Family History Initiative (www.hhs.gov/familyhistory)

This site offers an online family history tool that the user may complete and download to provide to their physician.

GENETIC COUNSELING RESOURCES

GeneTests (www.genetests.org)

GeneTests is a medical knowledge base that relates genetic testing to the diagnosis, management, and genetic counseling of individuals and families with specific inherited disorders. Its website contains a database of genetic diseases with summaries and diagnostic information, clinical descriptions, management details, resources and references.

Genetic Alliance: Advocacy, Education & Empowerment (www.geneticalliance.org)

Genetic Alliance is a national coalition of consumers, professionals and genetic support groups who voice the common concerns of children, adults, and families living with and at risk for genetic conditions. This site contains membership information and a searchable member directory, useful health resources, newsletters, and other publications. This is the nation's clearinghouse for newborn screening information.

Medical Genetics, University of Kansas Medical Center (www.kumc.edu/gec/geneinfo.html)

This website contains a surplus of information on many national and international birth defects and genetics/birth defects organizations (including links to these organizations' websites). Additionally, the site also contains referral information for those wishing to seek a health care professional concerning a specific birth defect or genetic disorder.

National Society of Genetic Counselors (NSGC) (www.nsgc.org)

NSGC is the leading voice, authority, and advocate for the genetic counseling profession. The "Consumer Information" section of their website explains the role of genetic counselors. The site also provides contact information for genetic counselors for those seeking a referral, both nationally and internationally.

PRECONCEPTION HEALTH

CDC Preconception Health (www.cdc.gov/preconception/index.html)

Learn what you need to know now to have a safe pregnancy and healthy baby with CDC's preconception health web portal, available for women who are of reproductive age.

CDC Folic Acid (www.cdc.gov/ncbddd/folicacid)

This site provides information on the importance of folic acid for the prevention of birth defects. Also featured are an online CDC folic acid publication order form, a FAQ section, folic acid fact sheets, and a quiz. The Spanish version features questions and publications for the Hispanic population.

HEALTHCARE PROFESSIONALS AND SCIENTIFIC RESEARCHERS

American Academy of Pediatrics (AAP) (www.aap.org)

This website provides online access to AAP's recommendations, research findings, and policy statements, which convey helpful tips and health information for parents and providers on all child health topics.

American Family Physician (www.aafp.org/afp/20020615/2507.html)

This website provides a comprehensive peer-reviewed cover article on preconception health care. It includes a patient handout on preconception health, a preconception health care checklist, and information on various elements of preconception health, including promotion of folic acid, assessment of genetic risks, carrier screening by ethnicity, congenital infections, environmental toxins, risk of prescription drug use during pregnancy, management of chronic maternal illnesses during pregnancy, exercise and nutrition, and psychosocial factors.

HuGE Net: The Human Genome Epidemiology Network (www.cdc.gov/genomics/hugenet/default.htm)

The HuGE Net represents a collaboration of individuals and organizations from diverse backgrounds that are committed to the development and dissemination of population-based human genome information. The website provides information about the HuGE Net and peer-reviewed synopses of epidemiologic aspects of human genes, prevalence of allelic variants in different populations, population-based disease risk information, gene-environment interaction, and quantitative data on genetic tests and services.

International Clearinghouse for Birth Defects Surveillance and Research (www.icbdsr.org)

This site is dedicated to sharing data, news and views on the research, monitoring, and prevention of birth defects. It provides information about the Clearinghouse, membership directory, publications/papers, and birth defects links for professionals and general audiences.

MMWR article on Preconception Health, April 21, 2006-55(RR06) 1-23

(www.cdc.gov/mmwr/preview/mmwrhtml/rr5506a1.htm)

This MMWR article offers 10 recommendations made by the CDC/ATSDR Preconception Care Group and Select Panel to improve preconception health and preconception health care in the United States. These recommendations include preconception doctor visits and providing additional care and interventions to those women who have been affected by adverse pregnancies and have identified health risks such as heart disease and diabetes.

National Birth Defects Prevention Network (NBDPN) (www.nbdpn.org)

The NBDPN is a national organization of individuals at the local, state, and national level working in birth defects surveillance, research, and prevention. This site offers organizational information, newsletters, a listserv, and related links to state birth defects monitoring programs and other national organizations.

National Center for Biotechnology Information (www.ncbi.nlm.nih.gov)

The National Center for Biotechnology Information advances science and health by providing access to biomedical and genomic information.

National Survey of Children with Special Health Care Needs (NS-CSHCN)

(www.childhealthdata.org/learn/NS-CSHCN)

This is a subset of the National Survey of Children's Health, a telephone survey of U.S. households sponsored by the Maternal and Child Health Bureau of the Health Resources and Services Administration. The purpose of the survey is to assess the prevalence and impact of special health care needs among children. Data are collected on indicators such as condition, impact on activity and schooling, health insurance coverage, and access. Find national and state profiles by factors such as sex, race, and health condition.

Pregnancy Risk Assessment Monitoring System (PRAMS) (www.cdc.gov/prams/)

PRAMS is a surveillance project of the CDC and state health departments. PRAMS collects state-specific, population-based data on maternal attitudes and experiences before, during, and shortly after pregnancy. A web-based query system (CPONDER) can be used to access national and state-level PRAMS data. Data sets are available for analysis. There is some variation from state to state. Some states do not participate. For more detailed data requests, also contact your state program. PRAMS data is a potential source for evaluating pregnancy experience regarding maternal risk factors that contribute to birth defects.

HEALTH EDUCATION FOR PHYSICIANS AND NURSES

MOD: Preconception Curriculum (<http://www.beforeandbeyond.org/?page=cme-modules>)

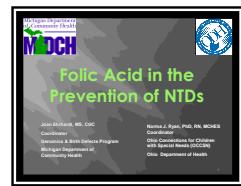
This website is designed for physicians providing health care to women who may become pregnant. Its curriculum includes a series of PowerPoint slide sets, a core module (which should be viewed first), and a separate module for each of the following four medical specialties: obstetrics/gynecology; internal medicine; family medicine; and pediatrics. There are also presentation notes included, which make this an educational tool that may be used as a teaching presentation for residents, fellows, nurses and primary care practitioners in clinical conferences, didactic sessions or Grand Rounds.

Preconception Self-Study Courses (<https://oh.train.org/DesktopShell.aspx>)

The Ohio Department of Health's Bureau for Children with Special Needs and Michigan Department of Community Health's Bureau of Disease Control, Prevention and Epidemiology are offering free educational self-study trainings for nursing and other health care providers interested in improving the preconception and interconception health of women of childbearing age (18-44 years). These self-studies provide information and resources addressing some common risk factors for poor reproductive outcomes, with a particular emphasis on recognizing and decreasing the risk for birth defects.

Folic Acid in the Prevention of NTDs

This course contains information about the importance of folic acid in the prevention of neural tube defects (NTDs); key strategies for helping women of childbearing age get the recommended amount of folic acid; trends among females of childbearing age in regard to folic acid knowledge, information about awareness and consumption that support the need for continued focus on client folic acid education, and professional resources and client education materials to increase folic acid knowledge and awareness. Nurses will receive 1.2 contact hours of continuing nursing education credits (CN#1028507) through the Ohio Department of Health for the course "Folic Acid and the Prevention of NTDS".



Having a Healthy Baby—Focus on Five

This course describes the public health impact of birth defects and the importance of focusing on preventable risk factors; identification of risk factors and prevention strategies that improve reproductive outcomes (this includes reducing the occurrence of birth defects); provider practices that can be implemented to recognize individual risks and support women of childbearing age in making healthy choices prior to conception; and resources for professional information and client support. Nurses will receive 1.60 nursing continuing education credits (CNE) of continuing nursing education credits [CN#1028474] through the Ohio Department of Health for the course "Having a Healthy Baby—Focus on Five".



MOD: Genetics & Your Practice Curriculum (www.marchofdimes.com/gyponline/index.bm2)

This website includes a curriculum designed for health care professionals and customized for those working with preconception/prenatal, infant/children, and adolescent/adult client types. It provides practical information and resources to assist the busy professional in integrating genetics into their patient care. A comprehensive array of information is provided under three topic areas: genetic testing and screening; family health and social history; and referral to genetic services.



PARENT SUPPORT GROUPS AND RESOURCES FOR SELECTED BIRTH DEFECTS

The information and resources listed are intended for educational use only and are provided solely as a service. The information provided should not be used for diagnosing or treating a health problem or disease, and is not a substitute for professional care. These links do not constitute an endorsement of these organizations or their programs by the National Birth Defects Prevention Network (NBDPN) and none should be inferred. The NBDPN is not responsible for the content of the individual organization web pages found at these links.

PUBLIC SERVICE ANNOUNCEMENT (PSA) AND PAPER FROM NBDPN PARENT ADVISORY GROUP

- NBDPN PAG Birth defects awareness public service announcement (PSA)
<http://www.youtube.com/NBDPN>
- NBDPN PAG article, "Insights from Parents about Caring for a Child with Birth Defects"
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3774449>

CENTRAL NERVOUS SYSTEM

Anencephalus/Anencephaly

- CDC's Anencephaly page
<http://www.cdc.gov/ncbddd/birthdefects/anencephaly.html>
- Medline plus: Anencephaly
<http://www.nlm.nih.gov/medlineplus/ency/article/001580.htm>
- Anencephaly Net
<http://www.anencephaly.net/>
- Yahoo Support Group
<http://health.groups.yahoo.com/group/anencephaly/>
- Anencephaly Information
<http://www.anencephalie-info.org/e/index.htm>

Spina bifida

- Spina Bifida Association of America (SBA)
<http://www.sbaa.org/>
- CDC's Spina Bifida pages
<http://www.cdc.gov/ncbddd/spinabifida/index.html>
- Medline Plus: Spina Bifida

- http://www.nlm.nih.gov/medlineplus/spinabifida.html
- SB-Parents
http://health.groups.yahoo.com/group/SB-Parents/
- Children with Spina Bifida: A Resource Page for Parents
www.waisman.wisc.edu/~rowley/sb-kids/
- Spina Bifida Association - St. Louis
http://www.sbstl.com/

Hydrocephalus

- Hydrocephalus Association
http://www.hydroassoc.org/
- Hydrocephalus Groups
http://health.groups.yahoo.com/group/HydroParents/
- Hydrocephalus Groups
http://health.groups.yahoo.com/group/hydrocephalus/

Encephalocele

- Children's Craniofacial Association
http://www.ccakids.com/
- FACES The National Craniofacial Association
http://www.faces-cranio.org/
- Fighters for Encephaly Defects Support (FEDS)
(412) 687-6437

Microcephalus/Microcephaly

- Microcephaly Group
http://groups.yahoo.com/group/microcephaly/
Email: microcephaly@yahoogroups.com
- Mild Micro Group
http://groups.yahoo.com/group/mildmicro/

EYE

Anophthalmia/Microphtalmia

- International Children's Anophthalmia Network
http://www.anophthalmia.org/
- Micro and Anophthalmic Children's Society
http://www.macs.org.uk/
- Microphthalmia Group
http://groups.yahoo.com/group/Microphtalmia

Congenital cataract

- Congenital Cataract
http://www.qualityhealth.com/health-encyclopedia/multimedia/congenital-cataract
- Cataracts Support Group
http://www.drugs.com/answers/support-group/cataract/
- Cataracts Support Group
http://www.dailystrength.org/c/Cataracts/support-group

Having a Baby with a Birth Defect: A mom's thoughts

At 19 weeks of her second pregnancy, Julie Mayberry and her husband were excited because they were having an ultrasound to learn the sex of their second child. They never imagined the test would reveal anything more dramatic; however, the Mayberry's were told their baby would be born with spina bifida.

The Mayberry's daughter was born December 26, 2001. She is now 13 years old and has enjoyed "dancing" with the help of her wheelchair since the age of 3, inspiring other children with disabilities to dance as well. Katie is a straight "A" student who also plays baseball, soccer, takes music classes, sings in the church choir, and goes to a spina bifida camp each summer.

There is nothing she has wanted to do, that we haven't been able to get her to do with some modifications. "Do I wish she did not have spina bifida and could run and play like other children? Yes. Life is tough for her. Simple things like pulling up her own pants can take a half-hour. She has had 15 surgeries and numerous hospitalizations because of infections," says Julie. "But our family has learned to appreciate the small things in life more. She has been a blessing to our family."

"I encourage other women to take 400 micrograms of folic acid if you are able to get pregnant, even if you are not planning a pregnancy. Studies have shown that it can help prevent spina bifida in many cases," said Julie. "If you've already had a child with a neural tube defect, it is recommended you take 4,000 micrograms of folic acid. That's what I did, and my next two children were not born with spina bifida."



Note: We thank Julie for giving us permission to share her family story

Aniridia

- Aniridia Foundation International
<http://www.aniridia.net/>
- Aniridia Foundation International Facebook
<http://www.facebook.com/pages/Aniridia-Foundation-International/183649933901>
- Aniridia Network
<http://aniridia.org/>

CARDIOVASCULAR

- Congenital Heart Information Network
<http://tchin.org/>
- Little Hearts
<http://www.littlehearts.org/>
- National Association for Children's Heart Disorders (NACHD): Kids With Heart
<http://kidswithheart.org/>
- Congenital Heart Defect Group
<http://health.groups.yahoo.com/group/congenitalheartdefectsupport/>
- It's My Heart
http://www.itsmyheart.org/index.php?option=com_content&view=article&id=137&Itemid=311
- American Heart Association
http://www.heart.org/HEARTORG/Conditions/CongenitalHeartDefects/Congenital-Heart-Defects_UCM_001090_SubHomePage.jsp
- Mended Little Hearts
<http://www.mendedlittlehearts.org/chdresources.shtml>
- Cove Point Foundation
<http://www.pted.org/>
- The Heart Institute for Children
<http://hope-pediatrics.com/hope/node/152>
- CDC's Heart Defect website
<http://www.cdc.gov/heartdefects>
- Medline Plus: Congenital Heart Defects
<http://www.nlm.nih.gov/medlineplus/congenitalheartdefects.html>

Common truncus

- HeartPoint
<http://www.heartpoint.com/congtruncus.html>
- CDC's Truncus Arteriosus webpage
<http://www.cdc.gov/ncbddd/heartdefects/truncusarteriosus.html>

Transposition of great arteries

- HeartPoint
<http://www.heartpoint.com/congtranspos.html>
- CDC's d-Transposition of the Great Arteries webpage
<http://www.cdc.gov/ncbddd/heartdefects/d-tga.html>

Tetralogy of Fallot

- HeartPoint
<http://www.heartpoint.com/congtetralogy.html>
- Medline Plus
<http://www.nlm.nih.gov/medlineplus/ency/article/001567.htm>

- National Heart Lung and Blood Institute
<http://www.nhlbi.nih.gov/health/health-topics/topics/tof/>
- CDC's Tetralogy of Fallot webpage
<http://www.cdc.gov/ncbddd/heartdefects/tetralogyoffallot.html>

Ventricular septal defect

- HeartPoint
<http://www.heartpoint.com/congvsd.html>
- Medline Plus
<http://www.nlm.nih.gov/medlineplus/ency/article/001099.htm>
- CDC's Ventricular Septal Defect webpage
<http://www.cdc.gov/ncbddd/heartdefects/ventricularseptaldefect.html>

Atrial septal defect

- HeartPoint
<http://www.heartpoint.com/congasd.html>
- Medline Plus
<http://www.nlm.nih.gov/medlineplus/ency/article/000157.htm>
- Atrial Septal Defect Survivors
<http://atrialseptaldefectsupport.org/>
Facebook: <http://www.facebook.com/asdsurvivors>
- CDC's Atrial Septal Defect webpage
<http://www.cdc.gov/ncbddd/heartdefects/atrialseptaldefect.html>

Atrioventricular septal defect (endocardial cushion defect)

- CDC's Atrioventricular Septal Defect webpage
<http://www.cdc.gov/ncbddd/heartdefects/avsd.html>
- Medline Plus
<http://www.nlm.nih.gov/medlineplus/ency/article/007324.htm>

Pulmonary valve atresia and stenosis

- American Heart Association
http://www.heart.org/HEARTORG/Conditions/CongenitalHeartDefects/AboutCongenitalHeartDefects/Pulmonary-Valve-Stenosis_UCM_307034_Article.jsp
- Medline plus
<http://www.nlm.nih.gov/medlineplus/ency/article/001091.htm>

Tricuspid valve atresia and stenosis

- Medline Plus
<http://www.nlm.nih.gov/medlineplus/ency/article/001110.htm>

Ebstein anomaly

- HeartPoint
<http://www.heartpoint.com/congepstein.html>
- American Heart Association
http://www.heart.org/HEARTORG/Conditions/CongenitalHeartDefects/AboutCongenitalHeartDefects/Ebsteins-Anomaly_UCM_307025_Article.jsp

Aortic valve stenosis

- Medline Plus
<http://www.nlm.nih.gov/medlineplus/ency/article/000178.htm>

- Mayo Clinic
<http://www.mayoclinic.com/print/aortic-valve-stenosis/DS00418/DSECTION=all&METHOD=print>

Hypoplastic left heart syndrome

- Children with HLHS
<http://health.groups.yahoo.com/group/childrenwithhlhs/>
- Medline Plus
<http://www.nlm.nih.gov/medlineplus/ency/article/001106.htm>
- CDC's Hypoplastic Left Heart Syndrome webpage
<http://www.cdc.gov/ncbddd/heartdefects/hlhs.html>

Patent ductus arteriosus

- HeartPoint
<http://www.heartpoint.com/congpda.html>
- Medline Plus
<http://www.nlm.nih.gov/medlineplus/ency/article/001560.htm>

Coarctation of aorta

- Medline Plus
<http://www.nlm.nih.gov/medlineplus/ency/article/000191.htm>
- CDC's Coarctation of the Aorta webpage
<http://www.cdc.gov/ncbddd/heartdefects/coarctationofaorta.html>

Anomalous pulmonary venous return

- American Heart Association
http://www.heart.org/HEARTORG/Conditions/CongenitalHeartDefects/AboutCongenitalHeartDefects/Total-Anomalous-Pulmonary-Venous-Connection-TAPVC_UCM_307039_Article.jsp
- CDC's Total Anomalous Pulmonary Venous Return webpage
<http://www.cdc.gov/ncbddd/heartdefects/tapvr.html>

OROFACIAL

Cleft palate, cleft lip

- Cleft Palate Foundation
<http://www.cleftline.org/>
- Children's Craniofacial Association
<http://www.ccakids.com/>
- American Cleft Palate-Craniofacial Association (ACPA)
<http://www.acpa-cpf.org/>
- Pierre Robin Network
<http://www.pierrerobin.org/>
- CleftClub.com
<http://health.groups.yahoo.com/group/cleftclub/>
- Cleft Talk
http://groups.yahoo.com/group/cleft_talk/
- Wide Smiles
<http://www.widesmiles.org/>
- Cleft Chat
<http://health.groups.yahoo.com/group/cleftchat/>
- FACES

- http://www.faces-cranio.org
- Cleft Lip and Palate Association
http://www.clapa.com/
- CDC's Cleft Lip and Cleft Palate webpage
http://www.cdc.gov/ncbdd/birthdefects/cleftlip.html

Choanal atresia

- Children's Choanal Atresia Foundation
http://choanalatresia.org/aboutccaf.html

GASTROINTESTINAL

Esophageal atresia, tracheoesophageal fistula

- EA/TEF Support Connection
http://www.eatef.org/
- Tef Vater Website
http://www.tefvater.org/index2.html

RECTAL AND LARGE INTESTINAL ATRESIA/STENOSIS

Imperforate Anus

- IA (Imperforate Anus) Parents Support Group
http://health.groups.yahoo.com/group/IA-parents/
- Rainbow Kids
http://specialneedsadoption.rainbowkids.com/Anal_Atresia_-_Imperforate_Anus.aspx
- Pull-Through Network
http://www.pullthrunetwork.org/

Pyloric stenosis

- Pyloric Stenosis Support
(www.cafemom.com/group/113668)
- American Pediatric Surgical Association
http://www.pediatricsurgerymd.org/Pyloric_Stenosis/4218.htm
- Infant Reflux Disease
http://www.infantrefluxdisease.com/forums/

Hirschsprung disease (congenital megacolon)

- National Digestive Diseases Information Clearinghouse (NDDIC)
http://digestive.niddk.nih.gov/ddiseases/pubs/hirschsprungs_ez/
- National organization for Rare Diseases (NORD)
http://www.rarediseases.org/rare-disease-information/rare-diseases/byID/727/viewAbstract
- The Mayo Clinic
http://www.mayoclinic.com/health/hirschsprungs-disease/DS00825

Biliary atresia

- American Liver Foundation
http://www.liverfoundation.org/abouttheliver/info/biliaryatresia/
- Biliary Atresia Network
http://health.groups.yahoo.com/group/BiliaryAtresiaNetwork/

GENITOURINARY

Renal agenesis/hypoplasia

- Potter's Syndrome
<http://www.potterssyndrome.org/>
- National Kidney Foundation
<http://www.kidney.org>
- American Association of Kidney Patients
<http://www.aakp.org>
- NIH/National Institute of Diabetes, Digestive & Kidney Diseases
<http://kidney.niddk.nih.gov/>

Bladder exstrophy

- Association for Bladder Exstrophy Community
<http://www.bladderexstrophy.com/>
- The Pull-Thru Network
<http://www.PullthruNetwork.org>
- Children's Hospital Boston
<http://www.childrenshospital.org/az/Site856/mainpageS856P0.html>

Obstructive genitourinary defect

- healthetreatment's Obstructive Genitourinary Defect community
<http://www.healthetreatment.com/community/obstructive-genitourinary-defect/>
- National Kidney and Urologic Diseases Information Clearinghouse (NKUDIC)
<http://kidney.niddk.nih.gov/kudiseases/pubs/newborns/>

Hypospadias

- CDC Hypospadias page
<http://www.cdc.gov/ncbddd/birthdefects/hypospadias.html>
- Hypospadias and Epispadias Association
<http://www.heainfo.org/>

MUSCULOSKELETAL

Limbs

- Helping Hands Foundation
<http://www.helpinghandsgroup.org/>
- Superhands Network
<http://www.superhands.us/>
- STEPS
<http://www.steps-charity.org.uk/>
- Limb Differences
<http://limbdifferences.org/>
- Adams Oliver Syndrome Support Group
Email: sandy.ivins@btinternet.com
- AOSSupport
<http://www-aosupport.org/>

Gastroschisis

- Avery's Angels

<http://www.facebook.com/averysangels#!/photo.php?fbid=10151175942114874&set=a.10150789513484874.464836.243044679873&type=1&theater>

- GEEPS
<http://www.geeps.co.uk/gastroschisis.htm>
- American Pediatric Surgical Association
<http://www.pediatricsurgerymd.org/Gastroschisis/4201.htm>
- Gastroschisis Support Group
<http://www.gastroschismiracles.webs.com/>
- CDC's Gastroschisis webpage
<http://www.cdc.gov/ncbddd/birthdefects/gastroschisis.html>
- Medline Plus
<http://www.nlm.nih.gov/medlineplus/ency/article/000992.htm>

Omphalocele

- CDC's Omphalocele webpage
<http://www.cdc.gov/ncbddd/birthdefects/omphalocele.html>
- Medline Plus
<http://www.nlm.nih.gov/medlineplus/ency/article/000994.htm>

Congenital hip dislocation

- Gillette Children's Specialty Healthcare
<http://www.gillettechildrens.org/conditions-and-care/developmental-dysplasia-of-the-hip-ddh/>
- Baby Center
http://community.babycenter.com/post/a25941553/congenital_hip_dislocation_anyone

Congenital diaphragmatic hernia

- CHERUBS
<http://www.cherubs-cdh.org/>
- Support Group
<http://groups.yahoo.com/group/cherubs/>

CHROMOSOMAL

Trisomy 13 & Trisomy 18

- Support Organization for Trisomy 18, 13, and Related Disorders (SOFT)
<http://www.trisomy.org/>
- Trisomy 18 (Edwards syndrome)Chromosome 18
<http://www.chromosome18.org/>

Down syndrome (Trisomy 21)

- National Down Syndrome Congress
<http://www.ndsccenter.org/>
- National Association for Down Syndrome
<http://www.nads.org/>
- Kids Health
http://kidshealth.org/parent/medical/genetic/down_syndrome.html
- The National Down Syndrome Society
<http://www.ndss.org/>
- CDC's Down Syndrome webpages
<http://www.cdc.gov/ncbddd/birthdefects/downsyndrome.html>

- Medline Plus
<http://www.nlm.nih.gov/medlineplus/downsyndrome.html>

FETAL ALCOHOL SYNDROME DISORDERS (FASD)

Fetal alcohol syndrome

- Family Resource Institute
<http://www.fetalcoholsyndrome.org/>
- FAS Forum
<http://health.groups.yahoo.com/group/FASForum/>
- FAS Link
<http://www.acbr.com/fas/faslink.htm>
- The Family Empowerment Network (FEN)
<http://www.pregnancyandalcohol.org/>
- Fetal Alcohol and Drug Unit (FADU)
<http://www.depts.washington.edu/fadu/>
- Fetal Alcohol Spectrum Disorders (FASD)
<http://www.fasdcenter.samhsa.gov/>
- Fetal Alcohol Syndrome Consultation, Education and Training Services (FASCETS)
<http://www.fascets.org/>
- CDC's Fetal Alcohol Spectrum Disorders webpage
<http://www.cdc.gov/ncbddd/fasd/index.html>

AMNIOTIC BANDS

Amniotic bands

- Amniotic Band Syndrome
<http://www.amnioticbandsyndrome.com/>
- Superhands Network
<http://www.superhands.us/>

FLYER: EVERY 4 ½ MINUTES, A BABY IS BORN WITH A BIRTH DEFECT.



A woman with dark hair tied back, wearing a dark green top, is shown from the chest up, gently holding her pregnant belly with her right hand. She is looking slightly to her left with a neutral expression. The background is a bright, slightly overexposed window.

**Every 4½ minutes, a baby
is born with a birth defect.**

We want to help you reduce that risk.

Learn more about prevention, detection, treatment and living with birth defects at www.cdc.gov/birthdefects and www.nbdpn.org.

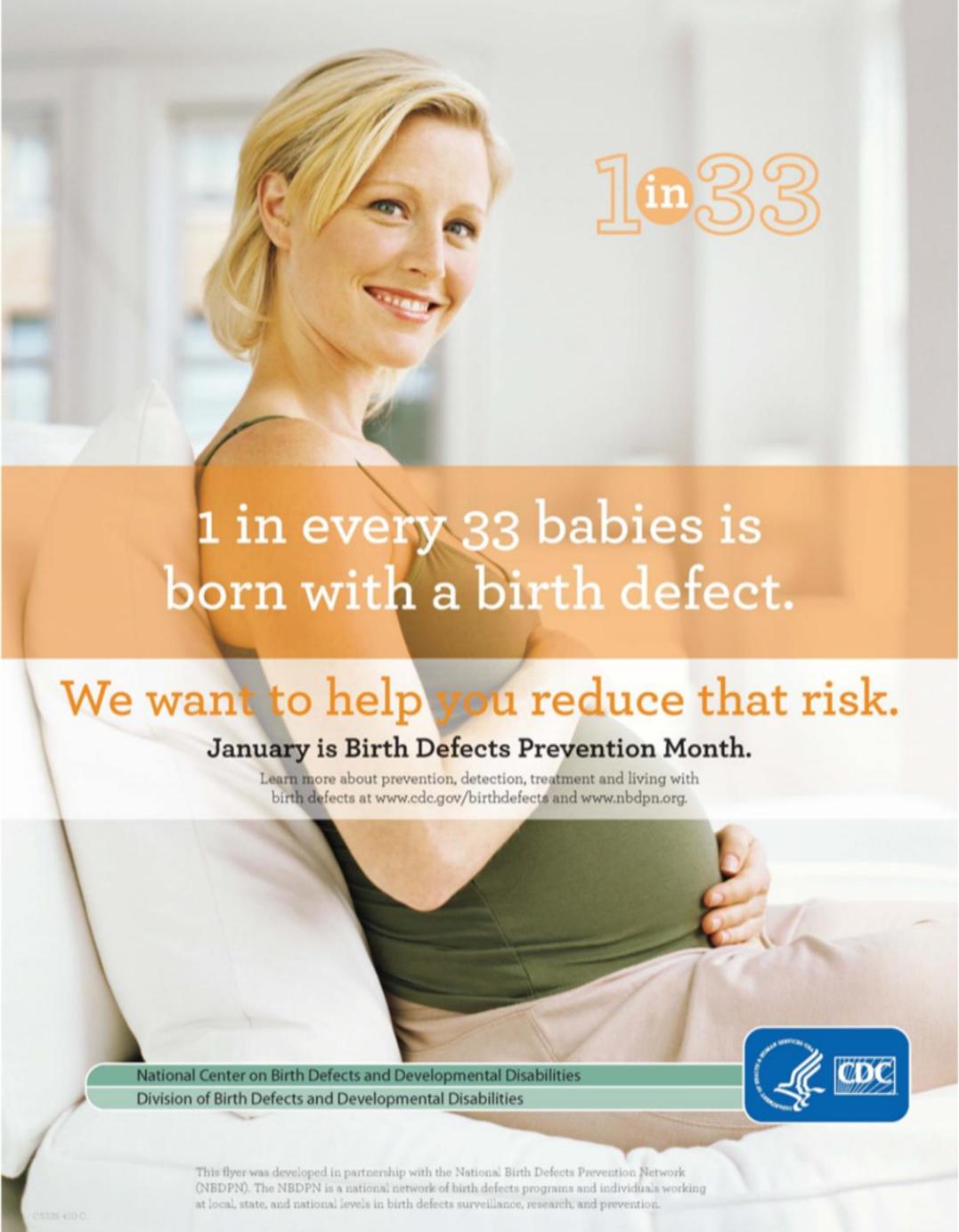
National Center on Birth Defects and Developmental Disabilities
Division of Birth Defects and Developmental Disabilities

This flyer was developed in partnership with the National Birth Defects Prevention Network (NBDPN). The NBDPN is a national network of birth defects programs and individuals working at local, state, and national levels in birth defects surveillance, research, and prevention.

C5206410-B

The CDC logo, featuring a stylized eagle with wings spread wide, perched atop a circular emblem with the words "Centers for Disease Control and Prevention". To the right of the emblem, the letters "CDC" are written in a bold, sans-serif font.

FLYER: ONE IN EVERY 33 BABIES IS BORN WITH A BIRTH DEFECT.



1 in 33

1 in every 33 babies is born with a birth defect.

We want to help you reduce that risk.

January is Birth Defects Prevention Month.

Learn more about prevention, detection, treatment and living with birth defects at www.cdc.gov/birthdefects and www.nbdpn.org.

National Center on Birth Defects and Developmental Disabilities
Division of Birth Defects and Developmental Disabilities

CDC

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CS28-400-C

FLYER: BIRTH DEFECTS AFFECT US ALL. WHAT EFFECT WILL YOU HAVE ON BIRTH DEFECTS?

Birth defects affect us all.



What effect will YOU have on birth defects?

■ 1 in every 33 babies is born with a birth defect each year.

■ The yearly hospital costs for birth defects exceed 2.6 billion dollars.

■ 1 in every 5 infant deaths occurs due to birth defects.

*Learn more about birth defects.
Visit www.cdc.gov/birthdefects and www.nbdpn.org.*

National Center on Birth Defects and Developmental Disabilities
Division of Birth Defects and Developmental Disabilities



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C3235410-A

APPENDIX 1: MATERIALS FOR LOCAL PUBLIC HEALTH DEPARTMENTS

National Birth Defects Prevention Network
Birth Defects Surveillance, Research & Prevention

2014 JANUARY IS NATIONAL BIRTH DEFECTS PREVENTION MONTH

Local Public Health Resource Packet

BDPM 2014

It is with great pleasure that we provide you with the materials designed for local public health agencies for the 2014 National Birth Defects Prevention Month. These materials were developed by the National Birth Defects Prevention Network's Education and Outreach Committee. These materials supplement a more comprehensive packet that includes a sample news release, proclamation, provider letters, resources on the internet, and parent resources.

National Birth Defects Prevention Month involves the efforts of many organizations. Building on our theme from last year, "Every 4 ½ minutes a baby is born with a birth defect," our goal for 2014 is to continue to build awareness that birth defects are "Common, Costly and Critical" and to offer actionable steps that can be taken by professionals, community groups, and the public to prevent birth defects. Birth defects affect 1 in every 33 babies born in the United States and are a leading cause of infant mortality. Babies who survive and live with birth defects are at increased risk for developing many lifelong physical, cognitive, and social challenges. Medical care and support services only scrape the surface of the financial and emotional impact of living with birth defects.

Please take the time to become familiar with the materials and complete the [Evaluation Form](https://www.surveymonkey.com/s/3FV7D9W) (<https://www.surveymonkey.com/s/3FV7D9W>). We hope you find them useful for the education, outreach, and prevention activities that you conduct in your community. Materials developed by NBDPN are available on the NBDPN website (www.nbdpn.org) and can be tailored to your specific agency's mission, needs, and capacity. Materials from the other organizations featured can be obtained directly from the organizations themselves.

If you should have questions about National Birth Defects Prevention Month, please contact Mary Knapp (Mary.Knapp@doh.state.nj.us) or Cara Mai (cmai@cdc.gov). We hope you find these materials helpful in providing information about birth defects to families, colleagues, and policy makers. *Thank you in advance for your support in promoting January as National Birth Defects Prevention Month.*

Sincerely,
Mary Knapp and LaShunda Williams
NBDPN Education & Outreach Committee Co-chairs

Local public health resource packet includes examples of:

- LPH1: Local public health announcement
- LPH2: Traditional letter to local public health agency administrators
- LPH3: Electronic letter to local public health agency staff
- LPH4: Brief awareness article
- LPH5: Awareness article for public health clinic newsletters
- LPH6: Announcement for electronic newsletters or listservs

LPH1: Sample Local Public Health Announcement “Plan Ahead”

Plan ahead for January 2014 – Birth Defects Prevention Month!

The theme of this year’s campaign is “Every 4 ½ minutes a baby is born with a birth defect.” We encourage you to begin thinking about activities you can do in your agency or community to raise public awareness of birth defects. The National Birth Defects Prevention Network (NBDPN) has developed a valuable packet of information. The materials help to raise awareness among health and public health professionals as well as the general public and will include posters, sample communication tools and resource sheets. Some ideas for use of the packet to raise awareness include:

- Put posters up in your agency waiting rooms, even restrooms!
- Provide fact sheets and posters on the importance of using folic acid to prevent certain types of serious birth defects.
- Volunteer to present information on birth defects and birth defects prevention at a “lunch and learn” with your MCH and Home Visiting Nurses, and other agency staff.
- Supply pamphlets or fact sheets for patients and professionals to doctors’ offices and clinics in the community.

Electronic materials will be sent as soon as they are ready. Please contact ([insert contact information](#)) if you would like more information.

LPH2: Sample traditional letter to local public health agency administrators

January 2014

MEMORANDUM

TO: Administrators, County Health Departments
District Nurse Managers (*Insert Other Recipients*)

FROM: (*Insert Name*)
(Department Director)

Birth defects are a leading cause of infant and childhood mortality. These conditions also place a considerable physical, emotional, and economic burden on individuals, families, and society-at-large. In (*name of state*), approximately (*insert number*) babies are born with a birth defect each year. I have included a State of (*name of state*) Birth Defects Profile (*if appropriate - as well as a Regional Birth Defects Profile*) for your reference.

January is National Birth Defects Prevention Month and this year's focus is on raising general awareness of the fact that "*Every 4 ½ minutes a baby is born with a birth defect*". Raising awareness of risk factors for birth defects, both among the public and the healthcare community, can help to significantly limit the occurrence of birth defects.

As you know, although not all birth defects can be prevented, the healthcare community can help all women, including teens, to lower their risk of having a baby with a birth defect and to avoid other complications of pregnancy by encouraging them to follow some basic health guidelines throughout their reproductive years, including:

- Consume 400 micrograms of folic acid daily
- Manage chronic maternal illnesses such as diabetes, seizure disorders, or phenylketonuria (PKU)
- Reach and maintain a healthy weight
- Talk to a health care provider about taking any medications, both prescription and over-the-counter
- Avoid alcohol, smoking, and illicit drugs
- See a health care provider regularly
- Avoid toxic substances at work or at home
- Ensure protection against domestic violence
- Know their family history and seek reproductive genetic counseling, if appropriate

You can make a difference in the lives of (*name of state*) families. Please review the materials in the attached packet and use them to promote awareness. We invite you to share these resources with coworkers, colleagues, staff, and others who might benefit from this information to raise public awareness of birth defects.

Thank you for your support. If you have questions or would like additional materials, please contact me or (*Insert Name*) at *xxx-xxx-xxxx* or by email (*Insert Email*) or (*Insert Email*).

LPH3: Sample electronic letter to local public health agency staff

Dear (public health nurses),

“Every 4 ½ minutes a baby is born with a birth defect.” The (name of state health department – hyperlinked to website) is joining the National Birth Defects Prevention Network (NBDPN) to raise awareness of the prevalence of birth defects and strategies that reduce the risk of birth defects and their complications. We hope that you will join us in promoting National Birth Defects Prevention Month and raising awareness of birth defects as a public health issue in your communities. Governor (name of Governor) has also proclaimed the month of January 2014 as Birth Defects Prevention Month ([hyperlink to state proclamation](#)). I invite you to share the resources I am sending you with coworkers, colleagues, local public health staff, and others who might benefit from this information.

Birth defects affect 1 in every 33 babies born in the United States and are a leading cause of infant mortality. Babies who survive and live with birth defects are at an increased risk for developing many lifelong physical, cognitive, and social challenges. Medical care and support services only scrape the surface of the financial and emotional impact of living with birth defects.

Although not all birth defects can be prevented, women can increase their own chances of having a healthy baby through healthy lifestyle choices and medical interventions before and during pregnancy. Please encourage all women who can become pregnant or are pregnant to lower their risk of having a baby with a birth defect by following some basic health guidelines throughout their reproductive years, including:

- Consume 400 micrograms of folic acid daily
- Manage chronic maternal illnesses such as diabetes, seizure disorders, or phenylketonuria (PKU)
- Reach and maintain a healthy weight
- Talk to a health care provider about taking any medications, both prescription and over-the-counter
- Avoid alcohol, smoking, and illicit drugs
- See a health care provider regularly
- Avoid toxic substances at work or at home
- Ensure protection against domestic violence
- Know their family history and seek reproductive genetic counseling, if appropriate

The (name of state – [hyperlink to birth defects program website](#)) Birth Defects Program website contains information, resources, and links to free educational materials from (name of state health department), Centers for Disease Control and Prevention, and the National Birth Defects Prevention Network. We encourage you to use these materials to raise awareness of birth defects prevention among health professionals and the general public in your community.

LPH4: Sample brief awareness article

January is National Birth Defects Prevention Month

"Every 4 ½ minutes a baby is born with a birth defect."

The (name of state/local) Department of Health is joining the National Birth Defects Prevention Network (NBDPN) and the (name of state) March of Dimes to raise awareness of the prevalence of birth defects and strategies that reduce the risk of birth defects and their complications. We hope that you will join us in promoting National Birth Defects Prevention Month. I invite you to share these resources with coworkers, colleagues, parents, and others who might benefit from this information.

Birth defects affect 1 in every 33 babies born in the United States and are a leading cause of infant mortality. Babies who survive and live with birth defects are at an increased risk for developing many lifelong physical, cognitive, and social challenges.

Although not all birth defects can be prevented, all women who could become pregnant or are pregnant can lower their risk of having a baby with a birth defect by following some basic health guidelines throughout their reproductive years. These include:

- Consume 400 micrograms of folic acid daily
- Manage chronic maternal illnesses such as diabetes, seizure disorders, or phenylketonuria (PKU)
- Reach and maintain a healthy weight
- Talk to a health care provider about taking any medications, both prescription and over-the-counter
- Avoid alcohol, smoking, and illicit drugs
- See a health care provider regularly
- Avoid toxic substances at work or at home
- Ensure protection against domestic violence
- Know their family history and seek reproductive genetic counseling, if appropriate

January is a perfect time to call additional attention to the importance of folic acid in preventing certain birth defects. The United States Public Health Service recommends that all women of childbearing age consume 400 micrograms (400mcg or .4mg) of folic acid daily to prevent up to 50 - 70% of neural tube defects, such as spina bifida and anencephaly.

The (name of state Birth Defects Program) has resource materials available on their website to assist you in raising awareness of birth defects as a public health issue in your clinic and communities. Materials include the NBDPN resource packet (*and insert name of state if appropriate* packet that can be tailored to meet your specific needs.) Included are sample partner and provider letters, proclamation, as well as links to parent and other resources.

For more information, contact (insert name and email)

LPH5: Sample awareness article for public health clinic newsletters

January is National Birth Defects Prevention Month

The **(name of state)** Department of Health is joining the National Birth Defects Prevention Network (NBDPN) to raise awareness of the prevalence of birth defects and strategies that reduce the risk of birth defects and their complications. This year's theme is "***Every 4 ½ minutes a baby is born with a birth defect.***"

Although not all birth defects can be prevented, the health care community can help all women (including teens) who could become pregnant or are pregnant to lower their risk of having a baby with a birth defect by encouraging them to follow some basic health guidelines throughout their reproductive years, including:

- Consume 400 micrograms of folic acid daily
- Manage chronic maternal illnesses such as diabetes, seizure disorders, or phenylketonuria (PKU)
- Reach and maintain a healthy weight
- Talk to a health care provider about taking any medications, both prescription and over-the-counter
- Avoid alcohol, smoking, and illicit drugs
- See a health care provider regularly
- Avoid toxic substances at work or at home
- Ensure protection against domestic violence
- Know their family history and seek reproductive genetic counseling, if appropriate

January is a perfect time to call additional attention to the importance of folic acid in preventing certain birth defects. The United States Public Health Service recommends that all women of childbearing age consume 400 micrograms (400mcg or .4mg) of folic acid daily to prevent up to 50 - 70% of neural tube defects, such as spina bifida and anencephaly.

You can make a difference in the lives of **(name of state)** families. Additional resources can be found on the [NDBPN website](#). If you have questions or would like more information, please contact **(name and email)**.

LPH6: Sample announcement for electronic newsletters or listservs

January is National Birth Defects Prevention Month and January 5-11 is Folic Acid Awareness Week

The (name of state) Department of Health is joining the National Birth Defects Prevention Network (NBDPN) to raise awareness of the prevalence of birth defects and strategies that reduce the risk of birth defects and their complications. We hope that you will join us in promoting National Birth Defects Prevention Month! This year's theme is "**Every 4 ½ minutes a baby is born with a birth defect.**"

The (name of state and birth defects program - hyperlink to birth defects program website) has resource materials available on their website to assist you in raising awareness of birth defects as a public health issue in your clinic and communities. Materials include the NBDPN resource packet and (name of state) resource packet that can be tailored to meet your specific needs). These materials contain sample partner and provider letters and proclamation, as well as links to parent and other resources. Free educational materials are also available from CDC at <http://www.cdc.gov/ncbddd/birthdefects/freematerials.html>

Folic Acid Awareness Week, January x -xx, is a perfect time to call additional attention to the importance of folic acid in preventing certain birth defects. The United States Public Health Service recommends that *all* women of childbearing age consume 400 micrograms (400mcg or .4mg) of folic acid daily to prevent up to 50 - 70% of neural tube defects, such as spina bifida and anencephaly. To learn more about Folic Acid Awareness Week go to ([link to website](#)).

For more information, contact (name and email).

Please see the complete packet for additional resources:

- **Sample News Release**
- **Sample Proclamation**
- **Sample Provider letters**
- **Resources on the internet**
- **Parent Support Resources**