Resource Column

Web Sites that Address Prematurity

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Abstract

Families of preterm infants need a tremendous amount of support. This resource column highlights several Web sites that may be useful to health care providers and childbirth educators, as well as to parents of premature infants and their families.

Journal of Perinatal Education, 13(1), 45–48; preterm infants, prematurity, Web resources, childbirth education.

Premature birth, defined as less than 37 completed gestational weeks, is increasing in many areas of the U.S. (Kearney, 2003). Infants born prematurely often experience a number of complications, including respiratory distress, necrotizing enterocolitis, and retinopathy of prematurity (Bakewell-Sachs & Blackburn, 2003). Premature birth is a stressful event for families. Women may blame themselves for the premature birth and the subsequent difficulties the infant experiences. At present, many causes of preterm birth are unknown. Known risk factors include the following: a previous preterm birth, poor nutrition and inadequate weight gain, smoking, environmental contaminants, multiple gestation, stress, obesity, unplanned pregnancy, young maternal age, poor maternal health, intimate partner violence, long hours and an extended period of standing in work roles, substance abuse, and infection (Gilbert & Harmon, 2002; Moore, 2003). Families of preterm infants need a tremendous amount of support. Many of the resources below provide avenues for support as well as information.

The Web sites identified below are categorized according to the intended audience. One Web site contains information that is relevant to both health-care providers and parents. This site is included in the section labeled

“Web Resources for Professionals and Parents.” This column is not meant to be a comprehensive list, but rather an identification of quality Web resources that address the topic of prematurity. The sites are listed alphabetically.

Web Resources for Professionals

American Academy of Pediatrics (AAP)

- <http://www.aap.org>

The American Academy of Pediatrics is the premier organization for pediatricians and others interested in pediatric health. Two items of interest for professionals on this site include policy statements: “Screening Examination of Premature Infants for ROP” (retinopathy of prematurity), which can be found at <http://aappolicy.aappublications.org/cgi/content/full/pediatrics%3b108/3/80>, and “Advanced Practice in Neonatal Nursing” at <http://aappolicy.aappublications.org/cgi/content/full/pediatrics;111/6/1453>. The AAP Web site also provides a wealth of information on general pediatric topics and offers a comprehensive list of policy statements.

American College of Obstetricians and Gynecologists (ACOG) News Release: Progesterone Recommended in Certain High-Risk Pregnancies to Help Prevent Preterm Birth

- <http://www.acog.org> (click on ACOG news release)

This link on the ACOG Web site cites a news release, published October 31, 2003, on using progesterone to prevent premature birth in some high-risk women. The basic premise of the news release is that women with a history of premature birth may benefit from progesterone in future pregnancies. ACOG’s opinion is based on two recent randomized placebo-controlled trials that are described in the news release. Contact information is provided for those who need additional information about the news release or the research.

Association of Women’s Health, Obstetric, and Neonatal Nurses’ (AWHONN) Prematurity Resource Center

- <http://www.awhonn.org/awhonn/?pg=873-9460>

AWHONN is a partner with the March of Dimes in the campaign to prevent prematurity. Therefore, much of the content on the AWHONN Prematurity Resource Center is similar to that listed on the March of Dimes

site (see below). However, the AWHONN site also includes information on additional initiatives that have been sponsored by AWHONN. For example, RBP6, or the Research Based Practice Program #6, is focused on smoking cessation as a mechanism to prevent prematurity and other pregnancy complications. In addition, the AWHONN site includes information on recently published articles on prematurity in the Association’s journals *Journal of Obstetric, Gynecologic, and Neonatal Nursing (JOGNN)* and *Lifelines*.

The Role of Environmental Hazards in Premature Birth: Workshop Summary

- <http://books.nap.edu/openbook/0309090652/html/index.html>

This Web site is the link to a newly released workshop summary by the National Academies of Practice. Downloading and printing are available free of charge. The Board of Health Sciences and the Institute of Medicine participated in the development of the workshop and this publication. The home page includes a table of contents or one can go to a specific page number. These features make it convenient to return to the site at a later date or to locate specific information. Hard copies of the publication may be ordered via the Web site. The Web site is easy to navigate and the content is presented in a way that is easy to skim. The table of contents includes the following sections, which can be downloaded and printed individually:

- front matter;
- summary;
- charge to participants and workshop core;
- problem statement;
- preterm birth and its consequences;
- labor and delivery;
- preterm birth—brief summary of biological pathways;
- preterm birth—gene-environment interactions;
- preterm-birth—social implications;
- future directions;
- abstracts;
- references;
- workshop agenda;
- speakers and panelists; and
- workshop participants.

Web Resources for Professionals and Parents

March of Dimes—Prematurity

- <http://www.marchofdimes.com/prematurity/prematurity.asp>

The March of Dimes is a nonprofit organization that strives to improve the health of newborns by preventing birth defects and infant mortality. The Web page is a comprehensive resource that offers information that is relevant to both parents and professionals. The home page includes the following sections: “Campaign to Prevent Prematurity”; “If You’re Pregnant”; “NICU families”; “Professionals and Researchers”; and “How You Can Help.” Each section includes detailed information on the topic of interest. The Web page also includes up-to-date statistics on premature birth throughout the U.S. The “If You’re Pregnant” section includes a nice description of the signs and symptoms of premature labor and what women should do if they experience symptoms. The site also includes information on assessing and reducing the risk for premature labor and provides prematurity stories. The March of Dimes also highlights November 18 as prematurity awareness day. The “NICU Families” section provides information for families on building confidence, getting adequate support, promoting attachment, and enhancing feeding practices.

The sections written for parents are simple and easy to read. For families with an infant in the NICU, simplicity is key, as these families are often stressed and overextended and cannot process complex information during the acute period of illness.

The section aimed at professionals and researchers includes materials that may be used in grand rounds sessions, prematurity statistics, and important health messages for patients and families. The “How You Can Help” section provides information on the fundraising campaign to prevent prematurity. Information is available on various events, including Walk America and other volunteer opportunities. The site also includes a search feature and sponsors (only a few) are listed at the bottom of the page so they do not interfere with content. Content on the site is current and the dates of the last revision are provided.

Web Resources for Parents and Families

Premature Baby—Premature Child

- <http://www.prematurity.org>

Giving birth to a premature baby is a traumatic experience that has fortunately seen many advances to support parents. Many sites are available on the Internet, but “Premature Baby—Premature Child” is especially impressive. A myriad of links to information provide parents with knowledge to guide them through their journey with their premature infant. This site includes references to books, stories by other parents, and research conducted in the area of prematurity.

The NICU itself is an intimidating environment, and the Web site offers comforting advice to parents who have never experienced a premature birth or intensive care. The link entitled “Surviving the NICU” provides a list of ways that parents can interact with their baby in the NICU and offers encouragement by noting the numerous technological advances that have been made.

Because premie parents are concerned about what the future holds for their baby, research information is available on the site as well. “Catch-up time,” speech issues, and other common questions about preemies are discussed in detail to help parents prepare for the years to come. Visitors to the site can also utilize the discussion board and listserv to chat directly with other parents for support and advice.

The main attraction of this site is the myriad of specific stories available. The site gives support not only through the positive influences of science but also through personal success stories from families around the country. The creators—parents of a premature infant themselves—found through experience that true, touching stories from other survivors are extremely beneficial. Beyond the research and past the books, the site offers a message that whispers, “We’ve been through this, and you will make it too!” The stories are the center of the site and provide helpful support to parents.

Premature Baby Resource Center

- <http://www.babyzone.com/drnathan/premature>

For parents of premature infants, the Premature Baby Resource Center is a site worth visiting. Dr. Nathan, a pediatrician with expertise in prematurity, created the site. He has 25 years of experience working with infants and children who are ill. The Web site includes information on premature infants, ways to communicate with staff at hospitals, and links to other useful sites. The following categories are listed on the home page:

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- introduction;
- glossary of terms;
- surviving the NICU;
- baby's graduation from the NICU;
- survival by birth weight;
- average length of hospital stay;
- talking with your child's doctor;
- problems with communication;
- dealing with your emotions;
- measuring prematurity;
- weight conversion chart;
- parent message board;
- true preemie stories;
- Web resources;
- intraventricular hemorrhage;
- understanding your baby's brain;
- posthemorrhagic hydrocephalus;
- transient tachypnea of the newborn;
- understanding levels of care; and
- periventricular leukomalacia.

Premature Baby Resource Center is an in-depth site that provides information to parents of premature infants. Like many Web sites, this site offers a message board for parents to form support groups. The site is current and

includes frequent updates. New content is clearly identified and dated. Unfortunately, the Web site features many advertisements.

This site is available to users on a consistent basis with a fast response time. A search engine is located on the left side of the page for users to type in search terms. Links to other reputable sites are provided along with a quality rank given by Dr. Nathan. Information on the site is logically organized, making it easy for the user to locate information. For questions not addressed on the site, Dr. Nathan accepts e-mail queries.

References

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