Resource Column

Web Site Resources for High-Risk Families

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Abstract

The Internet serves as an excellent resource for childbirth educators in their search for information and education to share with high-risk families who are in need of support to help them cope with complicated pregnancies.

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Welcome

Welcome to *JPE*'s new resource column! This column will serve as an information exchange of resources for childbirth educators. Each column will provide a variety of new resources, including web sites, book reviews, and other materials that childbirth educators may find helpful.

The goal of this column is to provide useful information for childbirth educators. This information may consist of professional resources or resources for families that come into contact with childbirth educators in their various roles. The resource information provided in this column will be as user-friendly as possible. This first column highlights Internet resources for high-risk families.

If you have an idea for a topic, contact Kristen Montgomery (krismontgomery@hotmail.com) or Lamaze International (1-800-368-4404).

Resources for High-Risk Families

While most pregnancies progress without difficulty and result in the birth of a healthy newborn, this is not always

the case. Each year, many pregnancies are complicated by problems such as premature labor, vaginal bleeding, and other medical complications in either the mother or fetus. Some of these problems are related specifically to the pregnancy; other times, a pre-existing condition contributes to the difficulty. A family's hopes for a happy pregnancy and perfect child may be lost. These families need support and education to help them cope with life's challenges. Childbirth educators may meet these women in classes before their crisis has occurred, after their crisis has resolved, during private home childbirth classes, during hospitalization, or in another role. Therefore, childbirth educators are in an excellent position to provide support and information for these families.

This issue's column focuses on Internet resources for high-risk families. Additionally, a few sites on "Kangaroo Care" are provided for professional caregivers who need to gain familiarity with the concept before recommending the resource to parents. The web sites identified here were carefully reviewed for content and usability and identified as the best resources for high-risk families. This list is not intended to be a comprehensive resource; instead, it may serve to name a few of the best sources that are currently online.

Kangaroo Care

Kangaroo Care involves placing a newborn skin-to-skin with his or her mother or another caregiver to enhance bonding and the transition to extrauterine life. Kangaroo Care was first developed in Columbia, South America, to help combat the country's high mortality rates for infants born preterm. Now, Kangaroo Care is often practiced immediately after delivery for all newborns, especially those that do not require immediate assistance. The following web sites are good resources for parents and professionals.

Resources for Parents

Kangaroo Care

<http://www.geocities.com/Heartland/Village/6554/index.html>

This web site was developed by a mother who experienced a preterm birth and practiced Kangaroo Care in the neonatal intensive care unit. The site is easy to use and written in the style of parent-to-parent. It contains various useful sections that offer succinct information

that is not overwhelming. Topics include history, links, how-to information studies, personal viewpoints, video information, bibliographies, abstracts, and how to contact leading Kangaroo Care nurse researchers, including Susan Ludington and Gene Anderson.

Kangaroo Care

http://www.umanitoba.ca/outreach/manitoba_womens_health/kangaroo.htm

This one-page site is sponsored by the University of Manitoba Hospital. Simple information is provided about Kangaroo Care. Different sections address the following questions: What is Kangaroo Care? Why Kangaroo Care? Where is Kangaroo Care practiced? When can Kangaroo Care be initiated? How do you do Kangaroo Care? Policies and procedures related to Kangaroo Care are provided; however, the policies reflect the standard at the University of Manitoba Hospital, which may differ from other facilities.

Resources for Professionals

International Network for Kangaroo Mother Care

<http://kangaroo.javeriana.edu.co/>

This is a professional organization that exists for the purpose of promoting Kangaroo Care. The site contains information on workshops, research projects, bibliographic references, a mailing list, and links. The site also provides detailed information on the mission and objectives of The Kangaroo Foundation, which supports Kangaroo Care research and training for health care providers. The site also offers information in Spanish.

Kangaroo Care Researcher Discussion List

<http://groups.yahoo.com/group/Kcare>

This resource serves as the home site to sign up for a listserv related to Kangaroo Care. The site is directed toward researchers interested in Kangaroo Care as a neonatal intervention.

Pregnancy Bed Rest

Pregnancy Bed Rest

<http://www.son.wisc.edu/~son/bedrest/index.html>

The Pregnancy Bed Rest web site was created to help women find information and resources on how to cope with bed rest. Dr. Judith Maloni, the leading nurse re-

searcher on pregnancy bed rest, developed the web site. Three main sections make up the bulk of this site and include parent stories, resources for families, and frequently asked questions. The resources section includes information on support groups, finances, legal issues, childcare, premie clothing, multiple birth, online support groups, and links to maintaining a normal life. The frequently-asked-questions section is detailed, yet simple, and covers a variety of important topics.

Sidelines National Support Network

<http://www.sidelines.org>

Sidelines is a national support network for pregnant women on bed rest. The organization's motto states, "When you find yourself on the sidelines, we're here to help." The "What is Sidelines?" section features information about the organization and its founders. Another area of the Sidelines web site allows women to request support by completing a web-based form. Women are matched with others who have had similar experiences.

Another section details articles on a variety of topics, including preterm labor, coping with bed rest, family issues, and childbirth class information. A 3-minute survey on preterm labor is available, along with links to helpful resources on how to remain occupied during bed rest.

A "letters" section provides interesting reading from women who were helped with Sidelines support. A highlight of this site is the chat list, which provides information on chat days, times, topics, moderators, and addresses to join.

Perinatal Crisis

NeoFight

<http://members.tripod.com/~Neofight/index.html>

Founded in 1976, NeoFight is a nonprofit support group for families experiencing a perinatal crisis. The web site specifically identifies the following crises: difficult pregnancy, miscarriage or stillbirth, birth of a premature or critically ill newborn, infants with special needs, and death of a child shortly after birth. The Indiana Chapter of the March of Dimes sponsors NeoFight. A toll-free phone number is prominently displayed at the top of the home page. Individuals may leave a message on the "neopager" and will be contacted within the hour.

Individuals needing assistance are matched with a trained, parent listener who has had a similar experience.

The site contains accurate, current information. Some of the main categories of the site include information on NeoFight's history and volunteer services, as well as local and national support groups for a variety of topics. Specific topics include infant loss, premature babies, children with special needs, twins and other multiples, subsequent pregnancy after loss, infertility, prenatal diagnosis, adoption, and newborn screening.

March of Dimes Health Library Resource Center

<http://www.modimes.org/HealthLibrary2/RC/Default.htm>

The March of Dimes provides accurate, timely information and referral services. The organization is composed of trained professionals who assist individuals, one-on-one, to address personal and complex problems in relation to reproductive health. A toll-free number is provided for the U.S. (1-888-MODIMES or 1-888-663-4637) and another number is provided for international assistance (001-914-997-4765). Features of the site include an index of fact sheets, links, and search capabilities. One highlight of the site is the section that provides information on general birth defects. This section includes information on The Children's Health Act of 2000, which established the National Center on Birth Defects and Developmental Disabilities. The fact sheets provided on the web site cover a variety of topics, including diabetes during pregnancy, low birth weight, stress and pregnancy, and specific birth defects. The frequently-asked-questions section includes information on each phase of the reproductive cycle, including preconception, pregnancy, and postpartum. Additional information is provided on safety and the warning signs of premature labor.

Prematurity

Parents of Premature Babies, Inc.

<http://www.preemie-L.org>

Parents of Premature Babies, Inc., is a nonprofit foundation that supports families with children born six weeks or more before their due date. The site contains sections that address the following topics: what's new, conference information (for parents), the preemie mentor program, resources for new parents, recommended

books, medical and Internet abbreviations, and frequently-asked questions. The highlight of this site is the preemie listserv to support parents and families. Instructions are provided on how to join, and guidelines and rules for the listserv are outlined. The preemie mentor program is available for those parents who need immediate and/or more personal support. This program provides focused, one-on-one support during the most critical period when parents may not be ready for the general support provided by the listserv. The program matches families who have had similar experiences and provides support via email for as long as desired. Volunteers who participate in supporting families undergo a training program. There is also an area for volunteers to sign up. Overall, the web site contains a wealth of information and is easy to use.

Coalition for Prematurity Awareness

<http://www.preemieawareness.org>

The mission of the Coalition for Prematurity Awareness is to form a united voice that promotes awareness of the incidence of premature birth in the U.S., as well

as preventable causes and possible consequences. Located in Wyoming, Michigan, the Coalition for Prematurity Awareness is a division of The Alexis Foundation for premature infants and children. The site has many sections that include the following topics: volunteer opportunities, preemie awareness news, joining the coalition, events, to-do list, papers, and links. Preemie awareness news features a mechanism to sign up for periodic e-mail updates and announcements. The papers section contains interviews and articles about prematurity. Overall, the site is easy to use, accurate, and up-to-date.

Summary

This review provides information on several key web sites for pregnant women who are considered high-risk. While childbirth educators may not be at the patient's bedside during an acute crisis, they are valuable resources for pregnant women and new mothers. Distribution of information during the childbirth curriculum can provide women with the resources necessary to cope with a high-risk pregnancy.

Resources for High-Risk Families

KANGAROO (skin-to-skin) CARE

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- Resources for Professionals
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PREGNANCY BED REST

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PERINATAL CRISIS

NeoFight
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March of Dimes Health Library Resource Center
<http://www.modimes.org/HealthLibrary2/RC/Default.htm>

PREMATURITY (birth before 37 weeks)

Parents of Premature Babies, Inc.
<http://www.preemie-L.org>
Coalition for Prematurity Awareness
<http://www.preemieawareness.org>

This box may be copied and used as a handout for expectant parents, compliments of Lamaze International (www.Lamaze.org).