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## CANCER RESOURCES IN THE UNITED STATES

The following list published in Oncology Nursing Forum (Vol. 20, No. 8, 1993) is compiled annually by the Oncology Nursing Society Education Committee. Cancer Care Associates, PC is providing this information as a service to our patients and colleagues.

NATIONAL, PUBLIC, PROFESSIONAL & PATIENT RESOURCES

American Cancer Society (ACS) 1599 Clifton Road, NE Atlanta, GA 30329-4251 404-320-3333 (general information) 404-329-7616 (Department of Nursing) (Phone numbers for local units and divisions are listed in the white pages of the telephone book)

ACS is a nationwide, community-based, volunteer health agency dedicated to eliminating cancer as a major health problem. Through research, education, and service, ACS not only helps prevent cancer but also saves lives and diminishes suffering from the disease. ACS has 57 divisions and 3,000 local units throughout the United States. The ACS publishes the newsletter Cancer Nursing News, which is mailed to nurses free upon request. Scholarships are available for master's degree and doctoral students in cancer nursing. Printed and audiovisual materials as well as educational programs are offered for nurses and other Healthcare professionals.

Other programs and services offered by ACS include:

Reach to Recovery - A rehabilitation program for women with breast cancer. A trained volunteer, who has already had breast cancer, offers emotional support and information to the newly diagnosed patient.

Ostomy rehabilitation program - A visitation program in which carefully trained volunteers, who have successfully adjusted to ostomy surgery, visit the newly diagnosed patient.

International Association of Laryngectomees - An organization that provides information and supportive materials for laryngectomees wish to offer supportive volunteer services to other people who have undergone a laryngectomy. Resources, information, and guidance

CanSurmount - A one-on-one visitation program for people newly diagnosed with cancer.

I Can Cope - A structured educational series that provides education and support to people with cancer and their families and friends.

Community Connection: Resources, Information, and Guidance (RIG) - A service program that provides the most current information about community and American Cancer Society resources for patients with cancer and their families.

Road to Recovery - A transportation program in which volunteers transport patients with cancer to and from cancer treatments. Cancer prevention and early detection programs for the public. Research grants and cancer control grants. Toll-free telephone number for cancer information (1-800-ACS-2345).

American Foundation for Urologic Disease, Inc. 300 West Pratt Street, Suite 401 Baltimore, MD 21201-2463 410-727-2908 410-528-0550 (fax)

The American Foundation for Urologic Disease, Inc., provides printed information to both the public and professional related to urologic problems, including cancer. The organization also provides information concerning the availability of scholarships for research that focuses on urologic problems.

Cancer Federation, Inc. 21250 Box Springs Road Moreno Valley, CA 92387 714-682-7989 714-682-0169 (fax) 1-800-982-3270

Cancer Foundation, Inc., supports and funds cancer immunology research programs at hospitals and research centers throughout the United States, offers scholarships to oncology trainees and researchers, supports various hospices, and provides referral information to patients with cancer and their families. It also publishes the quarterly magazine The Challenge and offers discounts on some books. Membership is \$20 a year.

National Black Leadership Initiative on Cancer (NBLIC) c/o Frank E. Jordan NBLIC Program Director Cancer Control Science Program Bethesda, MD 20892 301-496-8680 301-496-8675 (fax)

NBLIC is one of the National Cancer Institute's community outreach initiatives intended to increase cancer awareness among African-Americans. NBLIC offers individuals an opportunity to become part of a network of concerned and active African-American leaders across the United States who are bringing cancer prevention and control programs to African-American communities. Coalitions of NBLIC include national organizations, historically black colleges and universities, medical colleges, business and industry, media, and community-based programs. Chapters of national organizations and other local groups work together to mobilize community programs around the country.

National Coalition for Cancer Research (NCCR) c/o Marguerite Donoghue Capitol Associates Inc. 426 C Street NE Washington D.C. 20002 202-544-1880 202-543-2565 (fax)

NCCR is comprised of professional organizations, cancer research centers, and national lay organizations in the United States that are committed to addressing the research and public education efforts necessary to eradication cancer. NCCR represents more than: 10,000 survivors of cancer and their families, as well as the health professionals who care for them. 31,000 children with cancer and their parents and siblings. 65,000



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cancer researchers, nurses, and physicians. 76 cancer research centers.

NCCR is a coalition of key organizations in the cancer community that recognize that a coordinated approach among all cancer organizations is crucial to successfully addressing the scope of the cancer epidemic. This is best achieved by: Publicizing the value of cancer research and the major contributions that the National Cancer Program has made to basic biomedical science, patient care, and the reduction of cancer morbidity and mortality. Ensuring adequate funding to explore the opportunities that exist in cancer research. Increasing efforts to prevent and control cancer. Collaboration with other organizations to support effective public health policies that will assist in eradicating cancer (such as the Year 2000 Health Objective) and to educate policy makers about health hazards related to tobacco use.

United Ostomy Association (UOA) 36 Executive Park, Suite 120 Irvine, CA 92714 714-660-8624 1-800-826-0826

UOA is a nonprofit organization that provides speakers, literature, and monthly information meetings for people with ostomies. Volunteers, most of whom are ostomates, may visit patients with ostomies in the hospital or at home with the consent of the patient's physician.

Appearance Concepts Consulting Group (ACCG) 12543 Totem Lake Blvd., Suite 142 Kirkland, WA 98003

ACCG offers professional beauty consultation (specializing in the needs of women with cancer) and provides information on hair alternatives, makeup, skin care, and clothing. Training seminars are available to healthcare professionals, beauty and fashion professionals, and people with cancer and other cosmetic disabilities. ACCG also offers a collection of turbans and headwear. The founder of the company has written a book called Beauty and Cancer and concludes a series of seminars and workshops of the same name. Call or write for more information.

Cancer Care, Inc. 1180 Avenue of the Americas New York, NY 10036 212-221-3300

Cancer Care, Inc., is a nonprofit social service agency founded to help patients with cancer and their families cope with the impact of cancer. The organization provides psychological and financial support; counseling is available on both a group and individual basis.

Help for Incontinent People (HIP) P.O. Box 544 Union, SC 29379 803-579-7900 803-579-7902 (fax) 1-800-BLADDER

HIP is a nonprofit organization dedicated to improving the quality of life of people with incontinence. HIP is a leading source of education, advocacy, and support to the public and the health professional about the causes, prevention, diagnosis, treatments, and management alternatives for incontinence. HIP provides a wide variety of printed and audiovisual materials, including The HIP Report newsletter, the Resource Guide of Continence Products and services; a 33 minute videotape called "Bladder Control: How to Regain it; How to Maintain it"; and an audiocassette and booklet that coaches individuals through pelvic muscle exercises. Send a long, stamped, self-addressed envelope for an introductory packet about incontinence and for a list of HIP's publications and member services.

Look Good, Feel Better (LGFB) The Cosmetic, Toiletry, and Fragrance Association Foundation 1101 17th Street, NW, Suite 300 Washington D.C. 20036 202-331-1770

LGFB is a free national public service program dedicated to teaching women with cancer (through hands-on experience) beauty techniques that will help to restore their appearance and self-image during chemotherapy and radiation treatment. LGFB offers group or individual sessions conducted by trained and certified cosmetologists, complimentary makeup kits for patients participating in a group program, and free materials such as videotapes and pamphlets. In addition, LGFB materials are available in Spanish. The program is a joint venture of the Cosmetic, Toiletry, and Fragrance Association Foundation, the American Cancer Society (ACS) and the National Cosmetology Association. For information about program locations in your community, contact your local ACS office or call toll-free 1-800-395-LOOK.

Make Today Count 101 1/2 South Union Street Alexandria, VA 22314-3323 703-548-9674

Make It Today is an international organization for people with cancer or other life-threatening illnesses. It provides support groups and educational programs as well as brochures and handouts.

National Coalition for Cancer Survivorship (NCCS) 1010 Wayne Ave., Suite 300 Silver Springs, MD 20910 301-585-2616

NCCS is a network of independent organizations and individuals working in the areas of cancer support and survivorship. The primary goal of the coalition is to generate nationwide awareness of cancer survivorship. NCCS facilitates communication among people involved with cancer survivorship, promotes the development of cancer support activities, serves as a clearinghouse for information and materials on survivorship, acts as an advocate for survivors of cancer, and encourages the study of survivorship.

Oley Foundation 214 Hun Memorial, A23 Albany Medical Center Albany, NY 12208 518-262-5079 1-800-776-OLEY

The Oley Foundation offers support to consumers of home parenteral or enteral nutrition therapy and to their family members. The foundation provides patient/family support group meetings in various locations across the United States and publishes the monthly newsletter Lifeline Letter. The foundation also holds an annual



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international conference. The conference benefits consumers of home nutrition, their family members and friends, clinicians, and exhibitors by providing them with information and education as well as inspiration and support. Services are provided to consumers and their families free of charge.

US TOO Prostate Cancer Survivor Support Group US TOO International, Inc. One Heritage Plaza Building 7501 Lemont Road Woodridge, IL 60517 1-800-82-USTOO or 1-800-828-7866

US TOO provides various types of support for survivors of and patients with prostate cancer. The nonprofit organization offers information and counseling and conducts educational meetings to assist patients in the decision-making process. It has chapters across the United States and Canada that hold regular monthly meetings for patients with prostate cancer and their families. At these meetings, specialists in various fields provide information about prostate cancer and related surgery, radiation, medicine, nutrition, and psychology. Meetings are free of charge and open to family members, friends, and professionals in the healthcare field. US TOO is affiliated with the American Foundation for Urologic Disease and is recognized by the American Cancer Society as a national support group for survivors of prostate cancer and their families.

The Women's Cancer Network 2413 West River Road Grand Island, NY 14072

The Women's Cancer Network provides support, referral, and resource services to women who have or have had cancer. Support services offered include a monthly newsletter, a support group, and a telephone network for women confined to the home. An information resource and referral system provides information to women with cancer relating to their psychosocial or physical needs and to the healthcare system. Public and professional programs are offered in addition to the individuals, institutional, or agency consultations. The Women's Cancer Network provides a vehicle through which women can share cancer experiences, receive positive energy and support, learn from each other, acquire strategies for healing, and learn ways to survive the healthcare system.

## PROFESSIONAL ORGANIZATIONS/RESOURCES

Academy of Hospice Physicians 500 9th Street North, Suite 200 St. Petersburg, FL 33705 813-823-8899

The Academy of Hospice Physicians was formed in 1988 to provide a unique forum for discussion and education pertaining to the care of patients who are terminally ill. This international organization of physicians has the goal of establishing hospice medicine as an organized medical discipline and an important component of the healthcare system. The academy is dedicated to providing education, research, and support for

physicians who participate in the care management of patients who are terminally ill.

Agency for Health Care Policy and Research (AHCPR) AHCPR Publication Clearinghouse P.O. Box 8547 Silversprings, MD 20907 1-800-358-9295

A government organization of the U.S. Public Health Service, AHCPR has collected guidelines related to research on the management of acute and chronic pain. As of September 1993, a compilation of these guidelines on pain management will be available.

American Association for Cancer Education (AACE) Robert M. Chamberlain, PhD, Secretary University of Texas M.D. Anderson Cancer Center 1515 Holcombe Blvd. Houston, TX 77030

AACE provides a forum for healthcare professionals concerned with the study and improvement of cancer education at the undergraduate, graduate, continuing professional, and paraprofessional levels. The association conducts annual meetings and publishes the Journal of Cancer Education.

American Association for Cancer Research Public Ledger Building 620 Chestnut Street, Suite 816 Philadelphia, PA 19106-3483 215-440-9300 215-440-9313 (fax)

The American Association for Cancer Research is a nonprofit professional society of scientists engaged in cancer research. Founded in 1907 and incorporated in 1940, its purpose is "to bring together active investigators of the cancer problem for presentation and discussion of new or significant observations and to foster research in cancer and other phenomena of growth." The association pursues these goals through the publication of a semimonthly journal, Cancer Research, which is reported to be the most frequently cited scholarly journal in the cancer field; a molecular biology journal, Cell Growth & Differentiation, and a journal on the causes and prevention of cancer in humans, Cancer Epidemiology, Biomarkers, & Prevention. The association conducts an annual meeting at which scientists from all over the world present original scientific papers on basis and clinical cancer research. It also conducts a variety of smaller scientific meetings on selected topics in cancer research. All of these meetings provide a forum for the exchange of novel research ideas.

American Society of Clinical Oncology Robert E. Becker, Executive Director 435 North Michigan Avenue, Suite 1717 Chicago, IL 60611 312-644-0828

The American Society of Clinical Oncology promotes and fosters the exchange of information related to neoplastic diseases (with particular emphasis on human biology, diagnosis, and treatment) for physicians who are academically based or in private practice throughout the United States and other countries. The society publishes the Journal of Clinical Oncology.

American Society of Pain Management Nurses (ASPMN) P.O. Box 2162 Tucker, GA 30085

ASPMN is a nonprofit organization whose purpose is to unite "professional nurses dedicated to the constant endeavor of promoting the highest standards of care for patients of all ages experiencing acute, chronic, and



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malignant pain." Goals of ASPMN include promoting and providing education, encouraging professional development of pain management nurses, facilitating professional communication, encouraging scientific investigation in pain management, promoting delivery of high standards of care, speaking for nurses in legislation and government programs, and encouraging nurses to specialize in pain management.

CancerNetTM

NCI International Cancer Information Center Attention: Jean Baum Building 82, Room 123 Bethesda, MD 20892 301-496-4907 E-Mail address: cancernet@icicb.nci.nih.gov (Type HELP in the body of the mail message for information and instructions).

CancerNet is a service that enables health professionals to access cancer information from the National Cancer Institute (NCI) via Internet. CancerNet contains cancer information from the PDQ (Physician Data Query) data base. Users can access state-of-the-art treatment summaries written in basic language appropriate for the general public. Additionally, information is available concerning screening guidelines, supportive care, patient publications, and other NCI information services. CancerNet statements are available in English and Spanish. There is no charge for using CancerNet or Spanish CancerNet, which are both available 24 hours a day, seven days a week.

International Society of Nurses in Cancer Care Christopher Bailey, Secretariat Mulberry House, The Royal Marsden Hospital Fulham Road London, England SW3 6JJ 071-252-8171, ext. 2123 071-351-2191 (fax)

The purpose of the International Society of Nurses in Cancer Care is to advance and disseminate knowledge and understanding of cancer nursing. Membership in the society is open to cancer nursing societies, universities and institutions involved in cancer care, and other entities whose work affects or involves the care of people with cancer. Membership is not available to individuals. The society has attained advisory status with the United Nations, the World Health Organization, and the International Council of Nurses. In addition, it hosts a conference every two years attended by approximately 1500 nurses from around the world. About 70 groups currently participate in the society's business.

Intravenous Nurses Society (INS) 2 Brighton Street Belmont, MA 02178 617-489-5202

INS is a national, nonprofit, specialty nursing society dedicated to upgrading intravenous nursing practice through education, the establishment of standards, and the promotion of research in order to achieve the

highest level of care for patients receiving intravenous therapies.

League of Intravenous Therapy Education (LITE) 911 Oak Knoll, SE Warren, OH 44484 216-369-2945

Founded in 1972, LITE is the first organization for nurses, pharmacists, and other professionals active in IV therapy. LITE is a nonprofit multidisciplinary organization that serves its membership through chapter programs, meetings newsletters, and annual seminars. Individuals can earn contact hours or educational units by attending these offerings. LITE also has published Guidelines and Recommendations for Practice in IV Therapy.

Oncology Nursing Society (ONS) 501 Holiday Drive Pittsburgh, PA 15220-2749 412-921-7373 421-921-6565 (fax)

ONS is a professional nursing organization whose purpose is to promote the highest professional standards on oncology nursing. ONS provides support to oncology nurses and encourages study, research, and exchange of information. In addition to guidelines and standards for oncology nursing practice and education, the society publishes a journal, the Oncology Nursing Forum, and a newsletter, the ONS News, which are provided to members, ONS annually holds a national Congress and Fall Institute, and local chapters exist throughout the United States. ONS also has a computerized national speakers bureau and is an ANA-accredited approver and provider of continuing education credits.

PUBLIC GENERAL INFORMATION

Cancer Information Service (CIS) 1-800-CANCER

CIS can be accessed by telephone to provide answers to questions from the general public, patients and their families and health professionals. Information specialists at CIS are not physicians, but they can provide accurate, up-to-date, and understandable information about cancer causes, prevention, detection, diagnosis, treatment, rehabilitation, and research. In addition, CIS may know about cancer-related services and resources in local areas. Printed materials on many cancer-related topics are available to callers free of charge. Searches of the PDQ data base also are provided at no cost to the public and to healthcare professionals.

CancerFAX

NCI International Cancer Information Service Attention: Jean Baum Building 82, Room 100 Bethesda, MD 20892 301-402-5874 (on fax machine handset) 301-496-8880 (for technical assistance)

Using facsimile technology, the National Cancer Institute (NCI) has developed CancerFax. This service enables individuals to retrieve state-of-the-art cancer treatment information directly from NCI's comprehensive and current source of cancer information - PDQ data base. Two types of summaries are available; one that is written to meet the informational needs of healthcare professionals and one that is written in language geared toward the general public. Additionally, information is available on screening guidelines, supportive care, patient publications, and other information services provided by NCI. CancerFax statements are available in English and Spanish. There is no charge for the service itself; users pay only the cost of the telephone call to the CancerFax computer in Bethesda, MD. The service is available 24 hours a day, seven days a week.

Combined Health Information Database (CHID)



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Attention: Richard Pike National Institutes of Health Box CHID 9000 Rockville Pike Rockville, MD 20892 301-770-5164 (fax)

CHID is a computerized bibliographic data base developed and managed by health-related agencies of the U.S. government. It contains references to health information and health education resources, many of which are not referenced in any other computer system or print resources. CHID is intended to serve health professionals, patients, and the general public. Presently, CHID has 21 subfiles and more than 96,000 abstracted resources, including ones relating to the education of patients with cancer, cancer prevention and control, and other cancer-related issues.

Coping 2019 North Carothers Franklin, TN 37064 615-790-2400

Coping magazine is the only nationally distributed consumer magazine for people whose lives have been affected by cancer. The magazine's primary purpose is to empower the readers (be they patients or professionals) by providing the knowledge that they need to cope with the many issues confronting their daily lives. Coping aims to inspire patients and survivors, to assume greater responsibility for, and participation in, the many facets of the disease. The magazine is published bimonthly (six times a year). Subscriptions cost \$18 for one year (\$24 Canadian/foreign) and \$32 for two years (\$44 Canadian/foreign). To subscribe, write to Coping, 2019 North Carothers, Franklin, TN 37064 or call 615-790-2400.

Food and Drug Administration (FDA) Office of Consumer Affairs HFE-88 5600 Fishers Lane Rockville, MD 20857 301-443-3170

FDA is a consumer source of publications dealing with food-related subjects, FDA regulations, cosmetics, general medical drug information, medical devices, radiologic health, and health fraud.

National Cancer Institute (NCI) Office of Cancer Communications Public Inquiries Attention: Chris Thomsen Building 31, Room 10A16 Bethesda, MD 20892 301-496-5583

NCI, the U.S. government's top agency for cancer research, offers a variety of services and materials to patients, the public, and health professionals. All NCI patient education materials are free of charge.

Office of Minority Health Resource Center U.S. Department of Health and Human Services P.O. Box 37337 Washington, D.C. 20013-7337 1-800-444-6472

The Office of Minority Health Resource Center provides information relating to health-related resources, targeting Asians, Pacific Islanders, African- Americans, Hispanics/Latinos, and Native Americans at the federal, state and local levels. The center also provides various information services, a computerized date base of minority health-related publications/programs, and a resource persons network.

U.S. Department of Labor Occupational Safety and Health Administration (OSHA) Directorate of Technical Support 200 Constitution Avenue, NW Washington D.C. 20210 202-523-7047

OSHA is involved in the development and enforcement of occupational safety and health standards and strives to ensure safe and healthful working conditions for every worker in the United States. The directorate of technical support can provide information regarding work-related hazards and occupational injuries and illnesses.

Terminal Care Choice in Dying 200 Varick Street New York, NY 10014 212-366-5540

Choice in Dying, a nonprofit organization, provides information about living wills and durable power of attorney and advice and counseling (both legal and personal) about terminal care decision making.

Hospice Link Hospice Education Institute Suite 3-B, P.O. Box 713 5 Essex Square Essex, CT 06426-0713 1-800-331-1620 203-767-1620 (In Alaska and Connecticut)

Hospice Line provides information about hospice care and can refer patients with cancer and their families to local hospice programs.

National Hospice Organization 1901 North Moore Street, Suite 901 Arlington, VA 22209 703-243-5900 1-800-658-8898 (Hospice Helpline)

Hospice is care and support for terminally ill people and their loved ones. The National Hospice Organization is a nonprofit organization that provides literature and information about hospice care to patients and their families, as well as referral to other local, regional, and national resources.