s the number of people living with a diagnosis of cancer has grown in recent years, there has been a corresponding growth in the resources tailored to meet the needs of this special population. This directory provides a broad overview of the resources currently available in our community.

We have attempted to include most relevant resources in this publication but the directory is not intended to be a comprehensive listing of all resources available to patients. The purpose of the book is to provide a foundation of information and not to provide medical, legal or financial advice. Many of the organizations and services listed here have proven to be valuable for cancer survivors, their families and friends. Inclusion of a resource in the directory does not, however, represent an endorsement of that resource by the Scripps Cancer Center or Scripps Health. Resources are constantly changing so be aware that, although we update this directory on a regular basis, there are always a few listings that are outdated.

If you would like additional information regarding support services for people with cancer, contact the key Scripps Cancer Center staff members associated with each Cancer Center site. Their phone numbers are listed at the back of this directory.

Here at Scripps, we strive to provide superior health services in a caring and positive environment. We collaborate with others in our community to deliver a continuum of care with the goal of optimizing your health and overall quality of life. We know that a cancer diagnosis can present a unique set of physical and emotional challenges, and we hope that this particular publication provides you with information that will help make your journey a little easier. Good luck with your treatment.

Chris Van Gorder

President and Chief Executive Officer

Scripps Health



Healing is a matter of time, but it is sometimes also a matter of opportunity.

- Hippocrates

Directory compiled by:

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The Scripps Cancer Center: An Overview

ounded in 1999, the Scripps Cancer Center (SCC) ensures the coordinated delivery of oncology services throughout the Scripps system. In-patient oncology clinical care is provided at all five Scripps hospitals: Scripps Memorial La Jolla, Scripps Memorial Encinitas, Scripps Green, Scripps Mercy, and Scripps Mercy Chula Vista. For over 20 years these facilities have maintained cancer program accreditation through the American College of Surgeons Commission on Cancer. At each hospital site one-on-one support is the centerpiece of every patient's treatment plan. Out-patient oncology care is provided in private physician offices located near the five Scripps hospitals, and at Scripps Clinic. State-of-the-art radiation therapy services, located at Scripps Memorial Hospital La Jolla and at Scripps Clinic are available to all patients in the Scripps system who require this type of specialized treatment.

An active Blood and Marrow Transplantation (BMT) Program is located on a dedicated unit (3 North) in Scripps Green Hospital. Established in 1980, the Scripps BMT Program was one of the nation's first programs to administer the life-saving therapy known as stem cell transplantation. Today, Scripps Cancer Center oncologists perform more than 40 autologous and allogeneic stem cell transplants a year. In 2003, the Scripps BMT Program was recognized as an affiliated transplant center for the National Marrow Donor Program.

Support Programs

Through generous community support the Scripps Cancer Center is able to offer a wide range of support services and patient assistance programs. At all SCC sites oncology social workers or cancer care liaisons (registered nurses) provide counseling services and guidance regarding transportation, housing, homecare, financial benefits, emotional concerns and other issues. Free professionally facilitated support groups sponsored by the Cancer Center meet regularly at various locations to help patients and loved ones find support, guidance and encouragement. Free educational workshops are held at various sites. A popular ten-session expressive writing workshop is offered three times a year. For information about any of these services, contact one of the Cancer Center support staff members listed at the back of this directory.

Clinical Trials

Researchers are constantly searching for more effective treatments for cancer and hematologic disorders. When laboratory research shows that a new treatment has promise, doctors use it to treat cancer patients in clinical trials. These trials are designed to answer scientific questions and to find out whether the new approach is both safe and effective. Patients who take part in clinical trials make an important contribution to medical science and may have the first chance to benefit from improved treatment methods.

Clinical trials represent one of the most important avenues for progress in the treatment of cancer and hematologic disorders; therefore the Scripps Cancer Center participates in a wide range of clinical trials. Patients who are enrolled in these studies are closely monitored by Scripps

physicians and researchers directly involved in the studies. Before a cancer clinical trial can be conducted within the Scripps system it must first be reviewed and approved by a group of medical professionals and lay people who comprise the Scripps Cancer Center Institutional Review Board. Clinical trials must meet strict guidelines and are subject to ongoing review.

For more information about clinical trials offered through the Scripps Cancer Center, speak with your physician or call Scripps Clinical Research Services at 800-995-4200. Also, see www.scripps.org/clinicalresearch for a list of clinical trials currently being conducted by the Scripps Cancer Center.

Cancer Registries

Since 1975, the Cancer Registries at Scripps Hospitals and Scripps Clinic have been collecting cancer data regarding Scripps patients for research, epidemiological studies, education and patient treatment. Analysis of this data gives Scripps physicians the ability to measure the quality and effectiveness of the care cancer patients receive within the Scripps system. Data also aids in determining which programs of the Scripps Cancer Center should be developed or further expanded. To date there are over to 106,000 cases in the Scripps Cancer Registries database. The Registries annually conduct follow-up on more than 24,000 cancer survivors.

Information Resources



Your most important source for medical information is your physician, but there are also many excellent organizations, both national and local, staffed by caring and knowledgeable personnel who are ready to provide information regarding a wide range of cancer related topics.

American Cancer Society

S.D. County and national info. 800-ACS-2345 Imperial County (El Centro) 760-352-6656

2655 Camino del Rio N., Ste. 100 San Diego 92108

www.cancer.org

ACS provides free educational materials regarding cancer diagnoses and treatments, and sponsors support groups and a free volunteer transportation program for patients (see transportation section). Also *Reach to Recovery* and *Look Good...Feel Better* programs are provided for women - call for update on current programs. ACS position papers on unproven/alternative therapies can be reviewed on the ACS website. S.D. and Imperial County chapters maintain patient assist programs that reimburse for transportation costs with gasoline gift cards.

Blood and Marrow Transplant Information Network 888-597-7674

www.bmtnews.org e-mail: help@bmtnews.org

Provides publications (BMT Newsletter), support and BMT information.

BMT Link (National Bone Marrow Transplant Link) 800-LINK-BMT www.nbmtlink.org

BMT Link provides BMT info, publications and links patients with BMT survivors. Booklet, *Survivors' Guide for Stem Cell Transplant*, can be ordered or downloaded.

Brain Tumor Society

800-800-770-8287

www.tbts.org

Provides patient support, educational materials, and updates regarding conferences. Quarterly newsletter. Raises funds for brain tumor research. Provides *Support Line Network*, a national listing of brain tumor survivors who offer support to other patients, and *Brain Tumor Information Line*, a toll-free information service.

Breast Cancer

National Breast Cancer Coalition

800-622-2838

www.stopbreastcancer.org

Based in Washington, C.C., NBCC has, since 1991, lobbied for public policies that have a positive impact on breast cancer research, diagnosis and treatment.

Susan G. Komen Breast Cancer Foundation helpline: 800-462-9273

www.komen.org

Komen Foundation's goal is to save lives and end breast cancer forever by empowering people, ensuring quality care and energizing science to find the breast cancer cures.

Breast Cancer Network of Strength S.D. office: 858-625-4667

www.networkofstrength.org

Breast Cancer Network of StrengthTM, formerly known as Y-ME National Breast Cancer Organization®, is a Chicago-based national nonprofit organization with the mission to ensure through information, empowerment and peer support, that no one faces breast cancer alone. Peer counselors can be contacted at 1-800-221-2141.

cancereducation.com

www.cancereducation.com

Internet resource for professionals, patients, and family featuring audio and visual lectures, news on research and treatments, and information on many types of cancers.

Cancer Legal Resource Center

866-THE-CLRC (toll free), 213-736-1455

www.disabilityrightslegalcenter.org/about/cancerlegalresourcecenter e-mail: clrc@lls.edu

Provides free info and educational outreach on cancer-related legal issues for patients and families. A joint program of Loyola Law School in Los Angeles and the Western Law Center For Disability Rights. Free telephone assistance.

Fertility Resources

Scripps Clinic Fertility Center

858-554-8630

15004 Innovation Dr., San Diego, CA 92128 (Scripps Clinic RB) www.scrippsclinic.com (specialties/centers of excellence)

> The Center provides semen banking and a full range of fertility services under the direction of Jeffrey Rakoff, MD. For more info go to www.fertilityjourney.com/scripps.



Fertility Center of California

619-265-0102

6475 Alvarado Rd., Suite 109, San Diego

www.fertilityctr.com

"FCC" is a semen bank and reproductive lab serving physicians and their patients who require artificial insemination as well as those interested in storing semen to preserve future reproductive capacity.

Fertile Hope

888-994-HOPE

www.fertilehope.org

A non-profit organization founded in 2001 and acquired by the Lance Armstrong Foundation in 2009. Headquartered in New York, this organization is dedicated to providing reproductive information, support and hope to cancer patients whose medical treatments present the risk of infertility.

- ✓ Fertile Hope, Cryogenic Laboratories, and the Lance Armstrong Foundation have collaborated to produce *Live:On*, a sperm banking by mail kit for cancer patients. Call 800-466-2796 or visit http://:liveonkit.com for details.
- http://:myoncofertility.org is a patient resource provided by the Oncofertility Consortium that provides info, animations and cancer survivor videos regarding fertility issues.

National Kidney Cancer Association

800-850-9132

www.nkca.org

NKCA funds medical research, provides information to physicians and the public, and advocates on behalf of kidney cancer patients.

Leukemia & Lymphoma Society San Diego Chapter: 858-277-1800

Local: 9150 Chesapeake Dr., Suite 100, San Diego, CA 92123

www.leukemia-lymphoma.org

Provides educational materials on leukemia, lymphoma and multiple myeloma. Offers a Leukemia Support Group and maintains a Patient Aid program and a national copayment assistance program.

Lung Cancer Alliance

800-298-2436

www.lungcanceralliance.org

Based in Washington, DC, the LCA is dedicated solely to advocating for people living with lung cancer. Online survivor's community, phone buddy program.

Lymphoma Research Foundation 310-204-7043

www.lymphoma.org e-mail: LRF@lymphoma.org

LRFA's primary focus is funding for lymphoma research, but it also provides a slate of educational and support programs including an outstanding annual symposium and a lengthy selection of educational webcasts on their website. Free hotline and quarterly newsletter. A buddy program links newly diagnosed callers to patients with similar disease types who are interested in providing encouragement and support.

American Melanoma Foundation 619-448-0991

www.melanomfoundation.org

Based in El Cajon, CA, the AMF funds research in new treatments for melanoma.

International Myeloma Foundation

800-452-CURE

www.myeloma.org/myeloma/home.jsp

Based in Los Angeles, the IMF promotes education for physicians and patients about multiple myeloma. Funds research, holds clinical and scientific conferences, and publishes a quarterly newsletter, *Myeloma Today*.

National Cancer Institute (NCI)

800-4-CANCER

http://www.cancer.gov

The National Cancer Institute's Cancer website provides the latest cancer information to patients, their families, the public, and health professionals. Through their phone service, website and internet chat service the NCI provides information on treatment options, screening, prevention, supportive care, clinical trials, newly approved anticancer drugs and many drugs under investigation. NCI is the largest of the 13 institutes that make up the National Institutes of Health. NCI is our government's principle agency for cancer research and training. The national headquarters of the NCI is in Bethesda, MD.

National Center for Complementary and Alternative Medicine 301-402-4741

National Institutes of Health

http://nccam.nih.gov/

NIH Office of Alternative Medicine was established in 1992 stated with the goal of facilitating "the evaluation of alternative medical treatment modalities for the purpose of determining their effectiveness and to help integrate effective treatments into mainstream medical practice". In 1998 Congress changed the name of the OAM to the National Center for Complementary and Alternative Medicine. NCCAM sponsors research, conducts clinical investigations and serves as a public information clearinghouse.

National Coalition for Cancer Survivorship (NCCS) 888-650-9127

www.canceradvocacy.org

NCCS is the oldest survivor-led cancer advocacy organization in the country, empowering cancer survivors and advocating for quality cancer care.

National Lymphedema Network

800-541-3259

www.lymphnet.org

Based in San Francisco, NLN provides info, education and guidance on the management of lymphedema. Quarterly newsletter, toll-free support hotline and informative website.

National Marrow Donor Program

800-526-7809

http://marrow.org

NMBT, maintains a data bank of available tissue-typed marrow donor volunteers nationwide. The NMDP provides marrow transplants from unrelated donors to patients with leukemia and other blood disorders. Their Office of Patient Advocacy (www.marrow.org/patient, 888-999-6743) provides support and guidance through the transplant process.

National Ovarian Cancer Coalition (NOCC)

888-682-7426

www.ovarian.org

The mission of the NOCC is to raise awareness about ovarian cancer and to promote education about this disease.

Ovarian Cancer National Alliance

202-331-1332

www.ovariancancer.org

The mission of this group, based in Washington, DC, is to unite organizations in the fight against ovarian cancer. Publishes *Action Alliance*, a free quarterly newsletter.

Pancreatic Cancer Action Network (PanCAN)

877-272-6226 (El Segundo, CA)

www.pancan.org

Founded in 1999, PanCAN is a non-profit advocacy organization serving the pancreatic cancer community. Patient and Liaison Services (PALS) program offers provides info on pancreatic cancer, clinical trials and supportive resources.

(Prostate) Patient Advocates for Advanced Cancer Treatments (PAACT) 616-453-1477 www.paactusa.org

An independent information and advocacy organization for men with prostate cancer. Based in Michigan, PAACT publishes an interesting newsletter and makes available a large information packet on prostate cancer. Newsletter available online.

The Prostate Cancer Foundation 800-757-CURE

www.prostatecancerfoundation.org

The world's largest philanthropic source of support for prostate cancer research.

The Prostate Forum

800-305-2432

http://prostateforum.com

Monthly newsletter (\$46 a year) for prostate cancer patients written by Charles Myers, M.D. Dr. Myers worked for the National Cancer Institute for many years.

International Waldenstrom's Macroglobulinemia Foundation 941-927-4963 www.iwmf.com

Info and support regarding this rare cancer of the blood and immune system.

For information regarding local resources for seniors, check out the excellent **San Diego Eldercare Directory** online at http://eldercare.uniontrib.com/directory.

Support Services and Support Groups



A wide range of support services are now available to people living with a cancer diagnosis. Support groups can be found in various San Diego locations. Some are open to both patients and families, and some are open to patients only. Some are just for kids who have a parent with cancer. There are also groups for people with specific types of cancer. The Scripps Cancer Center, for instance,

sponsors a breast cancer support group in Encinitas and a gynecological cancers support group in the La Jolla area. The complete list of Scripps Cancer Center support groups is located at the end of this section.

Scripps Cancer Center also offers informative workshops on various topics. An ten-session *When Words Heal* expressive writing series is offered three times a year at Scripps Clinic. In partnership with Scripps Center for Integrative Medicine, a *Nutrition and Cancer* workshop is held three times a year in La Jolla. At Scripps Memorial Hospital La Jolla, the Cancer Center sponsors a weekly *Focus on Healing Through Movement and Exercise* program.

For more information about groups and supportive resources, contact one of the Cancer Center staff members on the phone list at the end of this directory, or check with the local office of the American Cancer Society. Information about Scripps programs can also be obtained by calling 1-800-SCRIPPS or by going to www.scrippscancercenter.org.

Association of Cancer Online Resources

www.acor.org

A non-profit organization that provides access to online cancer support groups and mailing lists for specific cancer types.

Access and Crisis Line

800-479-3339

The San Diego County Mental Health Crisis Hotline provides free phone counseling 24 hours a day for people in crisis.

Aging and Independence Services

800-510-2020

9335 Hazard Way, San Diego 92123

S.D. County Information and referral service for seniors, their families or anyone with questions about seniors. Access to case management programs, homemaker registry, health insurance counseling and other services.

American Cancer Society

800-ACS-2345

8880 Rio San Diego Dr., Ste. 100, San Diego 92108 www.cancer.org

Offers free support groups, supportive counseling, literature and other services, including "Reach to Recovery" and "Look Good...Feel Better" (See "Look Good...Feel Better")

Program".) ACS Cancer Survivors Network is an online community of survivors where you can create and share your on CSN web page (see www.acscsn.org). The local chapter of ACS maintains a comprehensive list of San Diego County cancer support groups.

BMT Support

www.bmtsupport.org

On-line support group for blood and marrow transplant patients and caregivers.

The Bone Marrow Foundation

800-365-1336

www.bonemarrow.org

Based in New York, the BMF offers financial assistance and emotional support to blood and marrow transplant patients and their families.

Breast Cancer

Scripps Polster Breast Care Center

800-727-4777

9850 Genesee Ave., Ste. 170, La Jolla

http://www.scripps.org/locations/hospitals__scripps-memorial-hospital-la-jolla/services/breast-care__breast-care

In addition to providing clinical breast care services, the Polster Center also provides free support groups and educational workshops. Groups for young women and for spouses have been offered.

Breast Cancer Solutions

866-960-9222

www.breastcancersolutions.org

This non-profit, based in Costa Mesa, provides financial assistance to individuals in Southern California who are undergoing treatment for breast cancer and who are unable to meet their basic living expenses.

Susan G. Komen Breast Cancer Foundation Helpline: 800-462-9273

Breast Cancer Network of Strength (formerly Y-ME) 708 799-8338,

Local: 760-839-1703

National: 135 S. LaSalle St. Suite 2000, Chicago, IL 60603 National Hotline: 800-221-2141 www.networkofstrength.org

Network of Strength is non-profit organization that provides information, hotline counseling, educational programs and self-help meetings for breast cancer patients, their families and friends.

YourShoes 24/7 Breast Cancer Support Center/Hotline

1-800-221-2141 (English)

1-800-986-9505 (Español) *interpreters available in 150 languages

Young Survival Coalition

www.youngsurvival.org yscandiego@youngsurvival.org

YSC is dedicated to the concerns and issues that are unique to young women with breast cancer.

California Smokers' Helpline

800-NO-BUTTS

www.californiasmokershelpline.org

A telephone helpline that helps people quit smoking. Funded since 1992 by the California Department of Health.

Cancer Care, Inc. and Cancer Care Counseling Line

800-813-4673

1180 Avenue of the Americas, New York, NY 10036

www.cancercare.org

This national organization based in New York City provides the Cancer Care Counseling Line, a toll-free service that offers free phone counseling with a Cancer Care oncology social worker. Phone support groups for patients and on-line internet support groups for patients and relatives are also offered (http://www.cancercare.org/get_help/online.php)

Cancer Detection Programs: Every Woman Counts (CDP: EWC)

800-511-2300

CDP: EWC helps underserved women receive free breast cancer screening and diagnostic services and cervical cancer prevention. The program is funded by a federal grant and state tobacco tax revenue. For qualifying info call the 800 number.

Cancer Legal Resource Center

213-736-1455, toll free: 866-843-2572

919 S. Albany St., Los Angeles 90015

www.disabilityrightslegalcenter.org/about/cancerlegalresourcecenter

A joint program of the Western Law Center for Disability Rights and Loyola Law School. Free info and advice regarding cancer-related legal issues. Download their *Legal Resource Guide* in the Resource section.

Cancer Support Community (CSS)

www.cancersupportcommunity.org

Uniting the Wellness Community and Gilda's Club Worldwide (in 2009), CSS provides support, education and hope to people affected by cancer.

Colon Cancer Alliance

212-439-1101

175 Ninth Avenue, New York, NY 10011

www.ccalliance.org

The goal of the CCA is to bring "the voice of survivors to battle colorectal cancer through patient support, education, research and advocacy."

Commonweal Cancer Help Program

415-868-0970

P.O. Box 316, Bolinas CA 94924

www.commonweal.org

Offers week-long retreats for people with cancer at their 60 acre site on the coast north of San Francisco. Activities include meditation, yoga, support groups and massage. Commonweal and its founder, Michael Lerner, Ph.D., were featured on the Bill Moyers PBS special "The Healing Mind". Rachel Naomi Remen, MD, is associated with Commonweal (www.rachelremen.com).

Depression

Excellent information about **depression** is available on the website of the **National Institute of Mental Health**. See **http://www.nimh.nih.gov/health/index.shtml** and click on depression. Interested in learning more about specific anti-depressant medications? Most newer medications have their own websites. See lexapro.com, paxil.com, remeron.com, etc. These sites are informative but they are produced by pharmaceutical companies so they are not unbiased: they are essentially educational marketing tools.

EcaP (Exceptional Cancer Patients)

814-337-8192

522 Jacksonville Park Dr., Meadville, PA 16335 www.ecap-online.org.

An organization based on the somewhat controversial books and beliefs of Bernie Segel, MD. EcaP holds retreats and seminars for both patients and medical professionals.

Healing Odyssey, Inc.

949-951-3930

23591 El Toro Rd., Suite 214, Lake Forest, CA 92630 www.healingodyssey.org

This non-profit organization offers semi-annual 3-day retreats for women with cancer at a retreat in the mountains north of Santa Barbara. Activities include groups, meditation, and "experiential learning exercises". Scholarships available.

Lance Armstrong Foundation

866-235-7205

www.livestrong.org

Founded in 1997 by cycling champion, Lance Armstrong, survivor of metastatic testicular cancer. Based in Austin, Texas, LAF provides info and tools people living with cancer need to "live strong".



Leukemia & Lymphoma Society, San Diego Chapter 85

858-277-1800

www.leukemia-lymphoma.org

A support group for people with blood related cancers meets in the local branch office on Chesapeake Drive in Kearny Mesa. *First Connection* peer support program matches patients with volunteer survivors with the same or similar disease.

Look Good...Feel Better Program (American Cancer Society) 800-ACS-2345

In this free ACS program, licensed cosmetologists help cancer patients enhance their appearance using a program developed especially for women undergoing chemo and radiation therapy. Offered throughout the year at various San Diego County locations, including at some Scripps sites.

Lung Cancer Alliance 800-298-2436

www.lungcanceralliance.org

LCA is the only national non-profit organization dedicated solely to advocating for people living with lung cancer. Programs include a quarterly newsletter, a "Phone Buddy" program, computer information searches, and a toll-free lung Cancer hotline.

National **Lymphedema Network** support hotline 800-541-3259

Organization based in San Francisco. Informative website: www.lymphnet.org.

Lymphedema Support Group

858-626-5213

This local group, facilitated by Bobbi Kinner, RN, meets monthly at Scripps Memorial Hospital La Jolla. Sponsored by the Scripps Polster Breast Care Center.

Lymphoma Research Foundation

310-204-7040

8800 Venice Blvd. #207, Los Angeles, CA 90034

www.lymphoma.org e-mail: LRF@lymphoma.org

LRF provides a helpline, a quarterly newsletter and a buddy program that links newly diagnosed callers to other patients. The pairings are based on cell type, stage and grade of disease, treatment, patient's age and geographical location.

Meals-on-Wheels Greater S.D., Inc. 619-260-6110 (four offices around S.D. County) www.meals-on-wheels.org

Provides home-delivered meals, a hot lunch and a cold supper.

Greater La Jolla Meals-on-Wheels 858-452-1391 (not affiliated with above organization)

San Diego **Multiple Myeloma Support Group** 858-273-5008, elliotrecht@san.rr.com www.multiplemyelomasandiego.org

Meets in the UTC area of La Jolla on the second Monday of the month. .

Oral and Head and Neck Cancer, Support for People with 800-377-0928 www.spohnc.org

SPOHNC is a patient-directed, self-help organization dedicated to meeting the needs of oral and head and neck cancer patients. Based in New York.

Prostate Cancer Support Hotline

800-82-USTOO

A counseling hotline that is a service of the American Foundation for Urologic Disease. The Foundation sponsors a local USTOO Prostate Ca support group. See www.ustoo.com for more info regarding USTOO! International.

Southern Caregiver Resource Center

858-268-4432

3675 Ruffin Rd., Ste. 230, San Diego

http://caregivercenter.org

SCRC helps families face the challenges of caring for adults through programs and services that address the emotional, physical and financial needs of family caregivers. Info and referral, counseling, support groups and other services are offered.

San Diego Access and Crisis Line

800-479-3339

24 hr. crisis line sponsored by County of San Diego.

Sarcoma Alliance

http://sarcomaalliance.org

Guidance, education and support. Bulletin board, chatroom, online support groups. Based in Mill Valley.

The Simonton Cancer Center

310-459-4434

P.O. Box 890, Pacific Palisades, CA 90272

www.simontoncenter.com

Offers a retreats in Santa Barbara based on the support modeldeveloped by the author of *Getting Well Again*. Website has good imagery/visualization exercises.

Team Survivor

310-829-7849

www.teamsurvivor.org

A national association for women cancer survivors that provides training and support for local Team Survivor organizations and promotes the concept of cancer wellness through exercise across. For info about the San Diego team, contact teamsurivorsd@yahoo.com.

✓ **MedicAlert** emblems and the MedicAlert 24-hour *Advantage Service* is available from MedicAlert, a nonprofit international emergency medical information service. Call 800-432-5378 or visit www.medicalert.org.

Kid's Corner

Resources for kids who have a family member with cancer

Camp Kesem 408- 242-7239 (Camp Kesem UCSD)

www.campkesem.org

Camp Kesem is a national organization run by college students that offers free summer camps around the country for kids with a parent who has (or has had) cancer. CK's one-week sleep away camps are a chance for kids 6 to 13 to have a fun-filled week with kids

who are facing similar challenges. UCSD has a Camp Kesem summer camp program at Big Rock Creek Camp near Big Bear. Info about the UCSD program can be accessed from the Camp Kesem national website.



CLIMB 760-796-3757

www.childrenstreehousefdn.org

Children's Lives Include Moments of Bravery (CLIMB®) is a support program developed by the Children's Treehouse Foundation, a national non-profit foundation based in Denver, dedicated to the emotional support of children who have a parent or grandparent with cancer. Groups meet weekly for six weeks for an hour and a half. Conversation and art are used to help children identify and express complex feelings in a supportive environment. Dinner is provided. The new Center for Compassionate Care of The Elizabeth Hospice offers CLIMB groups or workshops for children, teens and parents at different locations in the North County. Call Liz Sumner at 760-737-2050 for details.

Kids Konnected 949-582-5443

www.kidskonnected.org

A non-profit organization based in Laguna Hills that has programs for children at many locations in California. The goal of KK is to provide friendship, understanding, support and education to kids who have a parent with cancer. Support groups meet in La Jolla at the Family Center of La Jolla, 7301 Girard Ave., Suite 302. Groups meet on the second Monday of each month from 7 pm-8 pm. Children 4 to 18 years old are placed in age appropriate groups where they "learn about cancer, have some fun and find that they are not alone." For more info, contact Dr. Paige Sloane at 619-889-8019.

Helping Children When a Family Member Has Cancer is an excellent 24-page booklet for parents. Written by the executive director of CancerCare, Diane Blum, MSW, the booklet can be viewed or downloaded from CancerCare at www.cancercare.org/pdf/booklets/ccc helping children.pdf

- The American Cancer Society has a section on their website devoted to a range of topics dealing with how to help children when a family member has cancer. See www.cancer.org/docroot/CRI/CRI_2_6x_Children_and_Cancer.asp. ACS also has various publications that deal with helping kids who have a family member with cancer.
- ✓ Cancervive has produced a helpful little brochure written for kids titled When a Family Member Has Cancer. The brochure, which accompanies a video by the same name, can be downloaded from the Oncolink website (U. of PA Cancer Center) at www.oncolink.com/library/article.cfm?c=1&s=2&id=608
- ✓ Valuable advice for parents can be found on the website of the Parenting at a Challenging Time (PACT) organization: www.mghpact.org/parents.php. This site is for parents who are parenting while experiencing a serious illness. PACT is associated with the Massachusetts General Hospital Cancer Center.

Scripps Cancer Center Support Groups

Breast Cancer Groups for breast cancer patients only

Encinitas: Scripps Memorial Hospital – Encinitas (group held off-site)

Westlake Building, Ste. 307, 681 Encinitas Blvd., Encinitas

1st and 3rd Wednesdays, 7 - 8:30 PM Facilitator: Bunny Nedry, RN, BSN

Info: 760-633-7551 or nedry.bunny@scrippshealth.org

La Jolla: Young Women's Breast Cancer Support Group (age 40 and under)

Scripps Polster Breast Care Center, La Jolla

9850 Genesee Ave., Suite 170, La Jolla

First Tuesday, 11:30–1:00 PM, Third Tuesday, 6:30 – 8:00 PM

Facilitator: Beverly Mangerich, RN, MSN, CBPN-IC

Info: 858-626-5207 or mangerich.beverly@scrippshealth.org

Metastatic Cancer Group

La Jolla: Support Group for Women with Metastatic Cancer

Scripps Polster Breast Care Center, La Jolla

9850 Genesee Ave., Suite 170, La Jolla **Second Tuesday, 12:00 – 1:00 PM**

Info: 858-626-5207 or mangerich.beverly@scrippshealth.org

Gynecological Cancer Group *for gynecological cancer patients only*

La Jolla: Scripps Well Being Center, La Jolla

4305 La Jolla Village Dr., La Jolla (University Town Center)

1st and 3rd Thursdays, 10 - 11:30 AM

Info: 858-626-7623

Stem Cell Transplant Program Dinner Workshops workshop/groups featuring a

presentation by a Scripps transplant MD. Call for details.

La Jolla: Green Cancer Center (in Cancer Center conference room in Anderson

Outpatient Pavilion, Scripps Clinic) 10710 North Torrey Pines Road, La Jolla Offered approximately every three months

Facilitator: Tom Friedman, LCSW

Info: 858-554-9376 or friedman.tom@scrippshealth.org

• Please call to confirm times as times sometimes change.

• Scripps Cancer Center regularly offers free workshops at different hospital sites on a number of topics including nutrition, expressive writing, and yoga. Check www.scrippscancercenter.org or contact an oncology social worker or cancer care coordinator listed at the end of this book.

• For info about other cancer support groups in the San Diego community, call the American Cancer Society at 800-ACS-2345.

Transportation

Automobile/Van Transport





American Cancer Society Road to Recovery Program 1-866-444-7672

The ACS *Road to Recovery Program* provides volunteer drivers (if/when available) who transport cancer patients to and from cancer related medical appointments. Patients must be able to walk unassisted. 7 to 10 day advance notice is required.

Scripps Clinic RB/Green Hospital shuttle service 858-487-1800 x1705

Scripps Clinic RB contracts with Cloud 9 Shuttle Service to provide round-trip transport to the Scripps Clinic Torrey Pines campus from the Scripps Clinic in Rancho Bernardo (15004 Innovation Dr.). Two vans operate on Monday, Wednesday, and Friday with set arrival and departure times. A \$10 round-trip fee is charged for each passenger. To schedule a ride, contact Scripps Clinic Rancho Bernardo at 858-487-1800 x1705.

Lutheran Social Services/Caring Neighbors www.lsssc.org

When available, volunteers provide transport to medical appointments for disabled San Diegans and economically disadvantaged seniors.

San Diego 619-263-1384 Lemon Grove 619-698-1716 Escondido 760-737-8640 Chula Vista 619-425-4061

Rides and Smiles senior transport program

877-634-6537

 $http://www.jfssd.org/site/PageServer?pagename = programs_older_on_the_go$

Part of On the Go transport program, Rides and Smiles is a volunteer transport program of Jewish Family Service/San Diego for seniors (60 and over). \$20 enrollment fee. Serves the following zip code areas: 92037, 92064, 92111, 92127, 92128, 92129, 92131, 92117, 92121, 92122. \$5 to \$25 dollar donation suggested. Rides must be reserved at least one week in advance. Call for details and enrollment forms.

Senior Life Assistance San Diego 619-266-1350, N. County 858-674-4087,

Inland and Temecula 760-743-7469 www.seniorlifeassistance.com

A transportation and In-Home Care service serving the San Diego and Temecula areas.

Stride www.stridesd.org

A website that provides comprehensive information about San Diego County's public and private specialized transportation providers for the elderly and disabled.

✓ **Disabled Person Parking Placard** info is available online through the California DMV at http://www.dmv.ca.gov/pubs/brochures/fast_facts/ffvr07.htm. The application form can be downloaded from http://www.dmv.ca.gov/forms/reg/reg195.pdf.

- ✓ The Coaster (train) runs Monday through Saturday from Oceanside to San Diego and San Diego to Oceanside. There is a stop in Sorrento Valley with a shuttle to a bus stop in front of Scripps Green and Scripps Memorial La Jolla Hospitals. Call 1-800-COASTER or go to www.sdcommute.com/service/coasterpate.htm for more info.
- The American Cancer Society has a transportation expense reimbursement program that can reimburse up to \$250 annually for transportation costs, including public transportation and parking. They are currently reimbursing with gasoline gift cards. For Imperial County patients the annual reimbursement ceiling is close to \$600. Contact ACS for details or have your social worker/care coordinator submit a referral to ACS.
- ✓ ARC Transport Service provides transport to and from San Diego from the Imperial Valley. ARC can be reached at 760-337-8002. The American Cancer Society has a contract with ARC and can assist with transport costs, depending on financial need. Call 1-866-444-7672 for details.
- Cancer Care, Inc. of New York (www.cancercare.org) can sometimes provide cancer patients up to \$300 a year to help with the cost of travel for cancer treatments. To qualify you must live in San Diego or Imperial County and have limited assets (roughly less than \$9,000 for a single individual and less than \$12,000 for a couple). Funding is not always available. Cancer Care also has a **Multiple Myeloma Door-to-Door** program that pays that helps mm patients with transportation costs if financial criteria are met. Contact Cancer Care, Inc. for more info about these programs: 800-813-4673.
- Local **senior centers** often maintain listings of people who will drive for a fee. Many homecare agencies have staff, usually homemakers or companions, who can provide transportation, but it is fairly expensive around \$16 an hour and up, with a 2 to 4 hour minimum. Check in the Yellow Pages under "Home Health Services". Taxicabs and airport shuttle services are always an alternate option.

Paratransit Services for Disabled Adults (van transport)

In San Diego County there are three regional paratransit service providers: MTS (Metropolitan Transit Service) Access, MTS Suburban and North County Transit District Lift. These organizations serve five different areas in our county. Clients can travel through different regional jurisdictions by transferring from one paratransit provider to another. In order to utilize these services a person must first be certified as being ADA (Americans with Disabilities Act) eligible. Individuals whose physical/mental/cognitive abilities prevent them from being able to use public transportation are eligible for certification. A physician's documentation of disability is required.

To request an application for MTS Access, MTS Suburban, or North County Lift call 877-232-7433. Applications are mailed to the ADA office for processing. A verification of certification status is then mailed to the applicant. Applications can also be completed and submitted online at **ADARide.com**.

For more information regarding these programs, go to the MTS website at **www.sdcommute.com**, click on "rider information" and go to "special services". Also see Stride (**S**pecialized **T**ransportation **R**eferral & **I**nformation for the **D**isabled and **E**lderly at **www.stridesd.org**.

MTS Access/American Red Cross (Central S.D.) 1-888-517-9627 www.sdmts.com/MTS/MTS_Access.asp

Serving urban San Diego, MTS Access provides low-cost transportation to adults who meet ADA guidelines for disability. One-way trips cost \$4.50 and there is no charge for an approved Personal Care Attendant accompanying a qualified passenger. Vans have wheelchair lifts. Service extends to Scripps Clinic – Torrey Pines.

North County Transit District Lift/North County Lifeline 760-966-6500 www.gonctd.com/accessibility_lift.htm

Provides low-cost curb-to-curb wheel chair accessible van transportation for adults in the North County who are certified as disabled. An ADA application for certification must be completed. It takes about three weeks to receive your ADA certification by return mail. Rides usually must be reserved two weeks in advance. Service extends south to Scripps Clinic – Torrey Pines.

MTS Suburban/Laidlaw Transit Service East County (R.B., Escondido, El Cajon and South Bay) 800-921-9664 www.sdmts.com/MTS/MTS_Access.asp Van transportation for adults in the East County and South Bay who have ADA disability certification. Fare is \$3.50. Does not serve Scripps Clinic Torrey Pines directly, but can sometimes coordinate with MTS Access to transport patients to La Jolla.

✓ A number of private local companies provide wheelchair transport including Care-A-Van, Cloud 9 Shuttle, No Vacancy, TLC Medical Transport and Santa Fe Medical Transport.



AirLifeLine, Inc.

877-AIR-LIFE

www.airlifeline.com

AirLifeLine is a national association of volunteer pilots who fly patients and families in financial need to their places of medical treatment. The operations center is in Sacramento. Flights must be less than 1,000 miles. Pilots donate the entire expense of the mission. Patients must be able to board the plane, sit in a seat and wear a seatbelt. Ground transport must be arranged by and paid for by the patient.

Angel Flight West

888-4-AN-ANGEL

www.angelflight.org

This organization uses volunteer pilots who provide air transport for needy people with health problems. Pilots fly their own planes and absorb transport costs. Patients are responsible for ground transport. Patients must be medically stable to fly, able to board the aircraft without special assist, and able to fly in a non-pressurized cabin. Patients may be accompanied by a family member or friend. Requires minimum 5-day advance notice.

Corporate Angel Network

914-328-1313

www.corpangelnetwork.org

A non-profit organization based in New York that uses available seats on corporate aircraft being flown on business trips to provide free air transportation for cancer patients traveling to or from cancer treatment centers. Patients must be able to board the aircraft unassisted and may be accompanied by a family member or friend if space permits.

National Patient Travel Helpline

800-296-1217

www.patienttravel.org

A national clearinghouse of transport info for patients who cannot afford air travel for medical care. This service, provided by Mercy Medical Airlift in Virginia Beach, VA, makes referrals to all known appropriate charitable, charitably-assisted, and special "patient discount" commercial air transport services.

Internet Resources



An impressive amount of cancer-related information can be obtained on the internet. For general cancer info, it's best to start with a reputable website like Cancer.Net (American Society of Clinical Oncology), or the website of the National Cancer Institute (www.cancer.gov).

Not all information on the internet is accurate, reliable or current. (See www.quackwatch.com for information regarding the large number of websites promoting questionable medical therapies.) Remember that linked sites are not always equally trustworthy and that information shared in cancer discussion groups can be unreliable. Always carefully review with your physician any treatment decisions that you are making that have been significantly influenced by information that you have obtained on the internet.

Create your our own free website...

You can do it! It's easy! Several internet sites now enable cancer patients and caregivers to easily set up a free personal website to communicate online with family and friends - a great way to provide medical updates and receive encouragement. This is the wave of the future. Check it out! See www.caringbridge.org, www.mylifeline.org, and http://csn.cancer.org/.

American Cancer Society

www.cancer.org

This site has a wealth of info about the treatment, prevention and detection of cancer and also about the wide range of ACS services and resources available to people with cancer.

American Society of Clinical Oncology (ASCO) Cancer.Net

www.cancer.net

This ASCO-sponsored site for patients and families features reliable info about specific cancers along with daily updates regarding cancer news.

Association of Cancer Online Resources

www.acor.org

A non-profit organization that provides access to online cancer support groups and mailing lists for specific cancer types.

BMT Link (National Bone Marrow Transplant Link)

www.nbmtlink.org

Provides information and peer support to bmt patients and families. Online library. Also see **Explore BMT.org**, a one-stop resource developed by the National Marrow Donor Program. Links to many important BMT related organizations.

Brain Tumor Society (see under Information Resources)

www.tbts.org

Breast Cancer Answers

www.canceranswers.org

Produced by the non-profit Public Health Institute, this website features personal stories, artwork from people touched by breast cancer, and information on clinical trials including an innovative clinical trials matching system.

California Smokers Helpline

www.californiasmokershelpline

Sponsored by Calif. Dept. of Health. Local office at UCSD. Free info and materials.

CancerEducation.com

http://cancereducation.com

Provides patients and medical professionals with info primarily through MedClips streaming audio/video presentations.

Cancer Care, Inc. (See listing under Support Groups and Support Services.)

www.cancercare.org

This non-profit organization based in New York, offers on-line support groups for patients, and for partners and relatives, in addition to other services. Website has special sections on melanoma and cancers of the prostate, lung, colon, brain and pancreas.

Cancer.Net

www.cancer.net

An informative website created by the American Society of Clinical Oncology. Contains educational podcasts, videos and medical illustrations, in addition to info about specific cancers.

Cancer News on the Net

http://cancernews.com

A site dedicated to bringing patients and their families the latest information on cancer diagnoses and treatment. Edited by a radiologist. Lots of valuable links.

Cancerquest

www.cancerquest.org

A website dedicated to teaching patients and medical workers about the biology of cancer and cancer treatments. Founded by the head of the Emery University Biology Department. A valuable learning resource. Great graphics.

Chemocare

www.chemocare.org

This site, started by figure skater and cancer survivor, Scott Hamilton, is designed to provide the latest information about chemotherapy to patients and their families, caregivers and friends.

Careers and Cancer

www.careersandcancer.org

This comprehensive website addresses issues of cancer and employment, including legal and financial questions, how to write a resume and answer interview questions, job search tools, and how and when to share your cancer story with colleagues.

Clinical Trials Information

www.scripps.org/clinical research

Info on clinical research in the Scripps system. Includes listing of clinical trials being conducted at Scripps sites.

www.cancer.gov/clinicaltrials/

Clinical trials info section of the National Cancer Institute website.

www.cancernavigator.org

Local website funded by the County of San Diego maintains listings of local cancer clinical trials.

www.centerwatch.com

A Boston-based clinical trials listing service.

http://ClinicalTrials.gov

A service of the U.S. National Institutes of Health.

Colon Cancer Alliance

www.ccalliance.org

Offers patient support and educational services. Also see Cancer Care, Inc. at www.cancercare.org and National Colorectal Cancer Research Alliance at www.nccra.org.

Colon Cancer Network

www.colorectal-cancer.net

Disabled Parking Placard (California DMV)

http://www.dmv.ca.gov/forms/reg/reg195.pdf

Downloadable parking placard application.

National Kidney Cancer Association

www.kidneycancerassociation.org

Lance Armstrong Foundation

www.livestrong.org

Founded in 1997 by cycling champion, Lance Armstrong, survivor of metastatic testicular cancer. LAF provides info and tools people living with cancer need to "live strong".

The Leukemia & Lymphoma Society (see under Information Resources and Support Groups) www.leukemia-lymphoma.org

Alliance for Lung Cancer Advocacy, Support, and Education (see under Support Groups) www.alcase.com

ALCASE is a non-profit organization devoted to providing support and info to people affected by lung cancer. Based in Washington D.C.

National Lymphedema Network (see under Information Resources)

http://www.lymphnet.org

Lymphoma Information Network

www.lymphomainfo.net/lymphoma.html

Lymphoma Research Foundation (see under *Information Resources*)

http://www.lymphoma.org

Melanoma Patients' Information Page

www.mpip.org

Contains a research library, clinical trial center, bulletin board, chat room and patient registry. Lots of good info and support.

International Myeloma Foundation

www.myeloma.org

Excellent info and networking regarding multiple myeloma.

Myelodysplastic Syndromes Foundation, Inc.

www.mds-foundation.org

The MSF was established by an international group of physicians and researchers to provide an ongoing exchange of information relating to MDS.

National Cancer Institute Support Information

www.cancer.gov/cancer information/

Comprehensive website with info on specific cancers, clinical trials, support resources, literature, etc.

National Center for Complementary and Alternative Medicine (a center within the NIH) http://nccam.nih.gov/

An informative NIH-sponsored site. NCCAM's goal is to "facilitate the evaluation of alternative medical treatment modalities" to determine their effectiveness.

National Coalition for Cancer Survivorship

www.canceradvocacy.org

Excellent site sponsored by this important survivor-led cancer advocacy organization based in the Washington D.C. area. Includes cancer news, political advocacy updates, search resources, events info and essential info for survivors and caregivers.

NeedyMeds.com

www.needymeds.com

Information regarding pharmaceutical company Patient Assistance Programs for people who are unable to afford the cost of their medications.

Nutrition Information

Cancer Nutrition Center

www.cancernutrition.com

The website of Carolyn Katzin, MSPH, CNS, a consulting nutritionist to The Wellness Community for the past nine years.

Cancer Nutrition Information

http://web.cancernutritioninfo.com

Website of Suzanne Dixon, MPH, MS, RD, an internationally recognized expert on nutrition and epidemiology who is on the staff of the Univ. of Michigan Comprehensive Cancer Center.

Diana Dyer's **Nutrition Page**

www.cancerrd.com

This registered dietician and cancer survivor has an informative website with a mission of providing nutritional info and inspiration for cancer survivors. She also writes wonderful nutrition-focused blog: http://dianadyer.blogspot.com/

OncoLink

www.oncolink.upenn.edu/

This large, award-winning site was created in 1994 by the U. of Pennsylvania Cancer Center. Features current news and many topics of interest to patients and families.

National Ovarian Cancer Coalition

http://ovarian.org

NOCC is a leading ovarian cancer public information and education organization.

Ovarian Cancer National Alliance

www.ovariancancer.org

An alliance of the most active ovarian cancer organizations around the U.S. Also see "Ovarian Cancer Newsletter" under *Information Resources*.

Confronting **Pancreatic Cancer**

www.pancreatica.org

Information and resources regarding pancreatic cancer. Also see www.pancan.org, Pancreatic Cancer Action Network, a patient education and advocacy organization.

The National **Prostate Cancer Coalition** (NPCC)

www.fightprostatecancer.org

The NPCC was formed in July, 1996, with the goal of developing a patient-based national prostate cancer agenda. Also see CaPCURE.

The Prostate Cancer Foundation

www.pcf.org

PCF is the world's largest philanthropic source of support for prostate cancer research. PCF's goal: to find better treatments and a cure for recurrent prostate cancer. Founded in 1993 by Michael Milken.

Quackwatch

www.quackwatch.com

A site devoted to combating health-related frauds, myths, fads, and fallacies. It includes an expanding section on alternative cancer therapies. The site was created by Stephen Barrett, MD, a retired psychiatrist who is an author, editor and consumer advocate.

Scripps Cancer Center

www.scrippscancercenter.org

Info about the mission of the Cancer Center, programs, clinical trials, support services, Blood and Marrow Transplant Program, etc.

Testicular Cancer Info and Support (tc-cancer.com)

http://tc-cancer.com/

Women's Cancer Network

www.wcn.org

WCN was developed by the Gynecologic Cancers Foundation to help the public, and specifically women who have developed gynecologic cancers, to better understand these diseases, learn about treatment options, and gain access to new or experimental therapies.



- An informative collection of videos are viewable on the **Caring4Cancer** web site: go to **www.caring4cancer.com/go /videos**. Interviews with Scott Hamilton, Arnold Palmer, and Joe Torre; Randy Pausch's famous "Last Lecture"; nutrition web videos; and Dr. Jeremy Geffen's "The Seven Levels of Healing" lecture can all be viewed on this site.
- The **San Diego Eldercare Directory** is an excellent source of information regarding local resources for San Diego seniors. See http://eldercare.uniontrib.com.
- ✓ Three very cool websites for young adults with cancer:
 - http://stupidcancer.com
 - www.planetcancer.org
 - www.2bme.org (specifically for teens)

Employment Discrimination

If you have concerns about employment discrimination or employment rights, read *Working it Out: Your Employment Rights as a Cancer Survivor*, an informative 28-page publication of The National Coalition for Cancer Survivorship (www.canceradvocacy.org). The booklet can be ordered from NCCS (888-650-9127), or viewed and downloaded from the NCCS website: www.canceradvocacy.org/resources/publications.

The Americans With Disabilities Act (ADA) is a federal law that prevents disability discrimination in employment. The Act applies to private employers that employ fifteen or more employees for twenty or more calendar weeks in the current or preceding calendar year. The Act prohibits discrimination against a qualified individual with a disability and offers protection for both employees and job applicants. Comprehensive information about the ADA can be reviewed on the ADA website (US Department of Justice) at www.ada.gov.

The California Fair Employment and Housing Act is a law which may help Californians who are experiencing or who have experienced employment discrimination because of a diagnosis of cancer or a history of cancer. This act prohibits most employers from discriminating against cancer survivors. Under this law, all employers with five or more employees, labor organizations, apprenticeship or other training programs, and employment agencies are prohibited from discriminating against "physically handicapped' individuals, including those individuals with "handicapping" medical conditions such as cancer. The following actions may be unlawful if such actions are taken because an employee or job applicant is a cancer patient or survivor:

- a) Refusing to hire an applicant or refusing to select an applicant for a training program leading to employment.
- b) Firing an employee from his or her job or a training program leading to employment.
- c) Discriminating against an employee in terms of wages, working conditions, or privileges of employment ("privileges of employment" can include insurance coverage, disability benefits, and holidays/vacations.)
- d) Taking action or actions against an employee because he or she has filed an employment discrimination complaint.
- e) Refusing to classify properly or in other ways discriminating against an individual seeking employment through an employment agency
- f) Denying union membership or in other ways discriminating against union members.

If you decide that you want to take action against an employer that discriminated against you because of your cancer or history of cancer, you have several options ranging from informal and formal actions in the work setting, to filing a discrimination complaint with the state and, finally, to filing a lawsuit. The Department of Fair Employment and Housing is the California

agency that investigates employment discrimination complaints. A complaint must be filed with the appropriate DFEH office within one year of the employer's discriminatory act.

If you ultimately decide to file a lawsuit, it may be important, and in some cases required, that you can document that you have previously attempted to seek a resolution to your problem through informal and formal means at work and through a discrimination claim with the state. Generally speaking, the best approach is to pursue whatever administrative and informal options are available to you before filing a lawsuit, as these options often can lead to an early and less costly resolution of your problem. If you are considering a lawsuit, or if you are unsure as to which alternative or set of alternatives is best in your particular situation, you should speak to an attorney who practices employment discrimination law.

The California Department of Fair Employment and Housing can be contacted at 800-884-1684. Their website is www.dfeh.ca.gov. The phone number for the DFEH San Diego office at 1350 Front Street, Suite 3005 is 619-645-2698.

Can a prospective employer ask me if I have ever had cancer?

In most cases, no. Under federal law and most state laws, an employer has the right to know only if you are able to do the job at the time you apply for it. A prospective employer may not ask you about your health history unless you have a visible disability and the employer could reasonably believe that it affects your current ability to perform that job. An employer may ask you detailed questions about your health only after you have been offered a job.



Cancer Legal Resource Center 213-736-1455, toll free: 866-843-2572

e-mail: clrc@lls.edu

www.disabilityrightslegalcenter.org/about/cancerlegalresourcecenter

A joint program of the Western Law Center for Disability Rights and Loyola Law School. Free info on legal issues relating to cancer in the workplace, insurance coverage, managed care/HMO's, trusts and estates, custody/guardianship/conservatorship, government benefits, advanced directives.

Senior Citizens Legal Services 858-565-1393 8775 Aero Dr., Ste. 238, San Diego, CA 92123-1756

www.seniorlaw-sd.org

Provides free legal services to San Diegans who are 60 years of age and older. Services include assistance with court appearances, litigation, medical issues, and will preparation. Offices are located in San Diego, Oceanside, Chula Vista, El Cajon and El Centro. A lawmobile provides general legal services to seniors living in rural locations such as Ramona, Jamul, Julian, Borrego Springs and Pine Valley.

Complementary and Alternative Medicine (CAM)



The National Center for Complementary and Alternative Medicine (NCCAM) is the Federal Government's lead agency for scientific research on complementary and alternative medicine. NCCAM is one of twenty-seven institutes and centers that make up the National Institutes of Health within the U.S. Department of Health and Human Services. NCCAM's primary responsibility is the conduct and support of basic and clinical research studies, using well-established tools of

rigorous scientific design, conduct and oversight.

Examples of NCAM sponsored research include large, multi-center clinical trials; specialty research centers; studies of therapies from whole medical systems (e.g., Ayurvedic medicine and traditional Chinese medicine); and studies in the four domains of CAM: manipulative and body-based therapies, biologically based practices, mind-body medicine, and energy medicine. The Center carries out these activities independently and in collaboration with other NIH Institutes and Centers, other government agencies, domestic and international research institutions, and industry.

The following discussion of CAM is taken from the NCCAM website: http://nccam.nih.gov

What is complementary and alternative medicine (CAM)?

CAM is a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine. Conventional medicine is medicine as practiced by holders of M.D. (medical doctor) or D.O. (doctor of osteopathy) degrees and by their allied health professionals, such as physical therapists, psychologists, and registered nurses. Some health care providers practice both CAM and conventional medicine. While some scientific evidence exists regarding some CAM therapies, for most there are key questions that are yet to be answered through well-designed scientific studies--questions such as whether these therapies are safe and whether they work for the diseases or medical conditions for which they are used.

The list of what is considered to be CAM changes continually, as those therapies that are proven to be safe and effective become adopted into conventional health care and as new approaches to health care emerge.

Are complementary medicine and alternative medicine different from each other?

Yes, they are different.

- Complementary medicine is used together with conventional medicine. An example of a complementary therapy is using aromatherapy to help lessen a patient's discomfort following surgery. Meditation and gentle yoga are considered to be complementary therapies.
- Alternative medicine is used in place of conventional medicine. An example of an alternative therapy is using a special diet to treat cancer instead of undergoing surgery, radiation or chemotherapy that has been recommended by a conventional doctor.

What is integrative medicine?

Integrative medicine combines treatments from conventional medicine and CAM for which there is some high-quality evidence of safety and effectiveness.



Scripps Center for Integrative Medicine

10820 N. Torrey Pines Road, La Jolla **858-554-3300** www.scrippsintegrativemedicine.org

The Scripps Center for Integrative Medicine, founded in 1999, is located in the Shiley Pavilion immediately north of Scripps Clinic. The Center is one of the largest clinical programs in the country for integrative medicine. The medical director and co-founder is Dr. Mimi Guarneri, a board certified cardiologist who is an attending cardiologist at Scripps Clinic. The Center provides:

- Prevention and early detection strategies and lifestyle enhancement training
- Clinical care and treatment options utilizing mind, body and spirit
- Professional and community education
- Research in the use and validity of integrative medicine techniques.

Services available at the Center for Integrative Medicine include:

- Acupuncture and biofeedback
- Nutrition consultation
- Mindfulness Based Stress Reduction
- Yoga, Tai Chi and Qigong
- Integrative Cardiology and Healing Hearts Program
- Healing Touch and massage

The Scripps Mindfulness-Based Stress Reduction Course is an 8-week intensive training in the use of mindfulness meditation to help people cope better with stress, pain and illness. The program, modeled after the programs developed by Jon Kabat-Zin, PhD, at the University of Massachusetts Medical Center, is offered by the Scripps Center for Integrative Medicine (CIM). Classes meet in the Shiley Pavilion at 10820 N. Torrey Pines Road. For more information, contact the Scripps Center for Integrative Medicine at 858-554-3300 or visit www.scrippsintegrativemedicine.org.



- If you are taking herbal medicines, be sure to led your physician know. Some herbal medicines may interact with conventional medicines, including chemotherapy, and decrease their effectiveness or create other problems.
- The MedlinePlus website maintains a large database and info on supplements and herbs in addition to drug info. Medline is a service of the U.S. National Library of Medicine and the National Institutes of Health. See www.nlm.nih.gov/medlineplus/druginformation.html
- ✓ The Integrative Medicine division at Memorial Sloan Kettering Cancer Center in New York City provides informative info on herbs, supplements, botanicals and other products at www.mskcc.org/mskcc/html/11570.cfm.
- An excellent overview and discussion of many CAM therapies is available on the American Cancer Society website: www.cancer.org. Go to "Patients, Family and Friends", then to "Preparing for Treatment". Under "Making Treatment Decisions" click on "Complementary and Alternative Therapies" on the column on the left.
- More interesting info about CAM therapies can be found on the National Cancer Institute website: www.cancer.gov/cancertopics/treatment/cam
- ✓ Critical assessments of many CAM therapies can be found at www.quackwatch.com, a website created by Stephen Barrett, MD, a retired psychiatrist who is the vice president of the National Council Against Health Fraud.
- ✓ Links to important recent journal articles on CAM can be found on lungcanceronline.org. Go to "Treatment Options" and then to "Complimentary & Alternative Medicine".

✓ Many local bookstores sell CDs and DVDs on stress reduction, relaxation, wellness, imagery and related topics. **The Scripps Center for Integrative Medicine** also sells a selection of products dealing with these issues.



"Because people often experience illness as a loss of control over their bodies, gaining the ability to calm anxiety can restore a sense of connection that is revitalizing. The ability to relax deeply, to experience the release of tension, and to feel that your body can still provide pleasure is a powerful sign of hope when facing a life-threatening illness. Learning that you can achieve a state of relaxation at will brings a feeling of confidence that you are once again in touch with your body. In addition, relaxation itself is recuperative and can lead to a decrease in the need for some types of medication."

Neal Fiore, PhD

Psychologist, cancer survivor and founding member of The National Coalition for Cancer Survivorship

Insurance and Related Services and Benefits



California Department of Insurance Consumer Services 800-927-4357

www.insurance.ca.gov

Provides consumer insurance information and responds to complaints related to the insurance industry.

California Major Risk Medical Insurance Program (MRMIP) 800-289-6574 www.mrmib.ca.gov/MRMIB/MRMIP.html

A state-run program that provides up to 36 months of medical insurance to Californians who are unable to obtain insurance coverage on the open market primarily due to the presence of a pre-existing condition. Premiums are relatively high. The annual maximum benefits are \$75,000 per covered individual per calendar year and \$750,000 in a lifetime. After 36 consecutive months in the program, subscribers are required to leave MRMIP, but they have the opportunity to enroll into guaranteed coverage that health plans are required to offer. Premiums increase, but the annual benefits limit jumps to \$200,000. There is often a waiting list of several months for MRMIP, and there is a 90-day pre-existing exclusion period after acceptance into the program. Nonetheless, MRMIP does offer an important option to people who are otherwise uninsurable. MRMIP available health plans in San Diego County are Anthem Blue Cross PPO and Kaiser Permanente Southern California. The MRMIP handbook, rates and application can be viewed and downloaded at http://www.mrmib.ca.gov/MRMIB/MRMIPBRO.pdf. An excellent local resource regarding this program is insurance specialist John J. Rodee, 619-298-5177.

California Pre-Existing Condition Insurance Plan (PCIP) 1-877-428-5060 www.pcip.ca.gov

A federally-funded plan for medically-uninsurable Californians who have been without health insurance for six months or more. The plan will run through 2013 and is different than the California Major Risk Medical Insurance Program (MRMIP). The annual deductible is \$1,500, and annual out of pocket maximum is \$2,500. There is no annual or lifetime benefit cap. Monthly premiums are lower than MRMIP Blue Cross premiums. Scripps physicians are on the PCIP provider list. The provider is called "PCIP PPO Network". An excellent local resource for assistance with applying for this program is insurance specialist John J. Rodee, CLU, at 619-298-5177. People who cannot afford MRMIP or PCIP premiums should investigate eligibility for Medi-Cal or County Medical Services Program.

County Medical Services Program (CMSP)

www.sdcounty.ca.gov/hhsa/programs.ssp/county_medical_services 471-9660

San Diego: 858-492-4444,

North County:760-

A medical assistance program offered by the County of San Diego to indigent adults 21 through 64 years of age who are permanent residents of San Diego County and who meet strict CMS financial requirements. Green Hospital and Scripps Clinic do not accept CMS. To schedule an eligibility appointment, call 800-587-8118

Consumer Center for Health Education and Advocacy

877-734-3258

http://healthconsumer.org/index.php?id=411

1764 San Diego Avenue, Suite 200

A local program that helps people evaluate what health programs (Medi-Cal, CMS, etc.) they may be eligible for. Staff can also help consumers who are having disputes with their health insurance provider. Staff can provide assistance with appeals.

HICAP (Health Insurance Counseling and Advocacy Program) San Diego: 619-565-8772 www.seniorlaw-sd.org/hicap.html

A state program for Medicare beneficiaries that provides information regarding Medicare HMOs and Medicare supplements to help facilitate decision making regarding insurance options. Also info regarding the Medicare Part D Drug Benefit. A HICAP attorney can assist with Medicare and HMO appeals. Offices in San Diego and El Centro.

HIPP (Health Insurance Premium Payment)

www.dhs.ca.gov

A State program that pays health insurance premiums for Medi-Cal beneficiaries with high cost medical conditions, when it is cost effective to do so. To be eligible you must be on Medi-Cal with a share of cost of around \$200 or less, you must have current health insurance or COBRA, your policy must cover your high cost medical condition, and the average monthly savings to Medi-Cal from your health insurance must be at least twice the cost of your monthly insurance premiums. You may contact HIPP by email at HIPP@dhcs.ca.gov, or by fax at 916-440-5676

IHSS (In Home Support Services) www.sdihsspa.com

San Diego: 619-338-2558 North County: 760-480-3424

This county program for financially needy disabled people provides funds for homemaker/care providers to help with non-medical home assistance. Eligibility is the same as Medi-Cal. The number of worker hours assigned is based on illness severity.

Low Income Health Program (LIHP) 866-262-9881 (select "general info")

www.sdcounty.ca.gov/hhsa/programs/ssp/low_income_health_program

A SD County program that funds medical care for uninsured adult residents between 19 and 64 years of age who are not eligible for Medi-Cal and who meet LIHP financial requirements. Applications can be made at local HHSA Family Resource Centers.

Medi-Cal 866-262-9881

www.dhs.ca.gov/mcs

A state-run program primarily for people who are over 65 years of age and indigent, or who are under 65, indigent and permanently disabled Covers many medical and nursing home expenses. Indigent patients who are under 65 with dependent children also may be eligible for this program, managed in San Diego County by the San Diego County Department of Social Services. Indigent adults between 21 and 64 years of age who are not permanently disabled should apply for help through County Medical Services Program (CMS). Eligiblility criteria and the application process can be fairly complex and the approval process can take months. An informative Medi-Cal booklet is available from the State Department of Health Services – call your local Medi-Cal office for a copy. Application packets are available at Family Resource Centers located throughout S.D. County. For a list of addresses of centers go to: http://www2.sdcounty.ca.gov/hhsa/, click on Programs, Services, Medi-Cal, and Select a Facility.

Medicare (Social Security Administration)

800-772-1213

www.medicare.gov

A federal health insurance program of the Social Security Administration primarily for people 65 and older and for certain disabled people under 65 years of age. There are two main parts to Medicare (in addition to the Medicare Part D drug benefit and the Medicare hospice benefit). Part A is hospital insurance that helps pay for inpatient hospital care, skilled care in a nursing home, home health care and hospice care. Part B is medical insurance that helps pay for doctor's services, outpatient hospital services, medical equipment, and a number of other medical services and supplies not covered under Part A. Part A has deductibles and coinsurance, but most people do not have to pay premiums for Part A. Part B has premiums, deductibles, and coinsurance amounts that you must pay yourself or through coverage by another insurance plan.

Medicare provides basic protection against the cost of health care, but it does not pay all medical expenses or most long-term care expenses. A detailed Medicare handbook is available free of charge from the Social Security Administration office or on the HCFA website. Also see the HICAP listing above and www.caqhealthadvocates.org, a website of California Health Advocates, for more information.

Helpful information regarding the Part D drug plan can be found at www.medicarepartd.com. Two additional websites with excellent info are: www.medicareinteractive.org and www.medicarerights.org.

Medicare costs in 2012

Part A coinsurance:

- \$0 for hospital days 0-60 of each benefit period
- \$283 each day for days 61-90 of each benefit period
- \$566 per day for days 91-150 (lifetime reserve days total of 60 reserve days which are non-renewable).

- Part A hospital deductible is \$1,132 for each benefit period.
- Skilled Nursing Facility coinsurance: \$141.50 per day for days 21-100.

Part B monthly premium

- \$96.40 if beneficiary had SSA withheld in 2009.
- \$110.50 if new beneficiary in 2010 and had SSA withheld.
- \$115.40 for all others with income less than \$85,000.
- annual deductible: \$162.

National Insurance Consumer Helpline

800-942-4242

1001 Pennsylvania Avenue, NW, Washington, DC 20004

NICH helps consumers find insurance companies that fit their needs. NICH responds to inquiries about insurance issues, consumer complaints, and questions about where to find appropriate insurance.

Patient Advocate Foundation

800-532-5274

www.patientadvocate.org

Based in Virginia, this non-profit organization serves as a liaison between patients and their insurer, employer and/or creditors to resolve insurance, job discrimination, and/or debt crisis matters related to their diagnosis. Patient assistance program helps eligible patients with prescription and treatment co-payments.

Social Security Disability Social Security Administration: 800-772-1213 www.ssa.gov

A program of monthly cash benefits from the Social Security Administration for people who are unable to work for a year or more as a result of a disability. For adults, the Social Security law defines disability as the "inability to engage in *any* substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months." To qualify for Social Security Disability benefits the worker must have worked long enough and recently enough under Social Security. Benefits do not begin until the sixth full month of disability.

For people who are unable to apply in person at a Social Security office, phone interviews can be arranged. Applications can also be started online at www.ssa.gov/applyfordisability. A "Disability Starter Kit" can be downloaded. The application process is lengthy and requires considerable documentation. After collecting benefits for two years, recipients of SSD automatically become eligible for Medicare.

Social Security Disability Help Center

Downtown San Diego: 888-418-8860

www.ssdhelpcenter.org

SSD Help Center helps people complete and file SSD applications, and assists with the appeal process. No charge.

800-480-3287

www.edd.ca.gov

A program of cash benefits from the California Employment Development Department (EDD) for workers who are, for at least eight days, prevented from performing normal or customary work as a result of an illness or injury, and whose wages were subject to the state disability insurance tax. Application is done through the mail utilizing an application form available from most hospital social workers and cancer care liaisons. The approval process takes several weeks. Weekly benefit amounts are based on the wages paid during a specific 12-month base period explained in the EDD State Disability Insurance brochure. A claim form must be completed and mailed within 49 days of the date you became disabled or you may lose benefits. SDI checks are paid every two weeks up to a total of 52 weeks. Forms and brochures can also be downloaded from the SDI website: www.edd.ca.gov/Disability/DI_Forms_and_Publications.htm. A helpful overview of State Disability can be found at www.disabilitybenefits101.org/ca/.

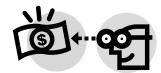
Supplemental Security Income (SSI) Social Security Administration: 800-772-1213 www.ssa.gov

This Federal income supplement program provides monthly cash payments for people in severe financial need who are 65 or older, or for people of any age who are disabled or blind. In order to be eligible for SSI an individual must have minimal regular cash income and minimal savings. If a person receives SSI payments, he or she usually receives Medi-Cal automatically. Food stamps are also a possibility. People on SSI and Medi-Cal who require assistance at home may be eligible for services through the In-Home Support Services program of the county welfare department.

- Helpful information about disability benefits available to Californians (Social Security Disability, State Disability, etc.) can be found at www.disabilitybenefits101.org/.
- ✓ Info about cash aid, food and medical assistance including food stamps, CalWORKS (welfare), Medi-Cal and County Medical Services Program is available at www.benefitscalwin.org.
- ✓ An excellent source of information regarding long-term care insurance is the website of the California Partnership for Long-Term Care at www.dhs.ca.gov/cpltc/.
- A valuable overview of insurance, personal finances and government benefits for people with cancer can be found on the **Survivorship A to Z** website. Go to: www.survivorshipAtoZ/cancer/.

Benefits CalWIN (www.benefitscalwin.org) is a website that outlines cash aid (CalWORKS/welfare), nutrition (CalFresh/food stamps) and medical (Medi-Cal) benefit programs available in California. Programs are listed by county.

Special Financial Help



- Cancer Financial Assistance Coalition (www.cancerfac.org) is a coalition of important organizations that help cancer patients manage their financial challenges: co-pay assist, premium assist, pharmacy costs, etc. Search for organizations that help with specific cancer diagnoses on this site. The site also includes a "reading room" on financial topics.
- **NeedyMeds.org** maintains an excellent list of patient assistance programs that are listed by specific diseases. See http://www.needymeds.org/copay_diseases.taf?
- **Breast Cancer Solutions** is a non-profit organization, based in Costa Mesa, that provides financial assistance to individuals in Southern California who are undergoing treatment for breast cancer and who are unable to meet their basic living expenses. Call 866-960-9222 or go to www.breastcancersolutions.org
- The Leukemia and Lymphoma Society Patient Aid Program provides supplemental financial assistance to patients with financial need who are receiving active treatment for their blood-related cancers or disorders (leukemia, lymphoma, Hodgkin's disease, multiple myeloma, MDS, aplastic anemia). The program helps to defray expenses for approved medications, radiation therapy, transportation transfusions and testing not covered by insurance. For details and an application, speak with a Scripps Cancer Center social worker or cancer care liaison, or call the local chapter of the Leukemia and Lymphoma Society (858-277-1800).
- CancerCare, Inc. of New York (www.cancercare.org) offers a financial assistance program for financially strapped cancer patients who reside in San Diego and Imperial Counties. Depending on availability of funds, Cancer Care will provide up to \$300 a year for transportation or childcare costs, and up to \$275 per year for homecare, pain medication, chemotherapy or radiation therapy charges that are not covered by insurance. Eligibility criteria for this program are based on liquid assets and marital status:

Single: \$9,000 maximum liquid assets Married: \$12,000 maximum liquid assets

Married with dependents: \$15,000 maximum liquid assets

IRA, 401k and 403b plans are not considered to be a liquid asset. For more information call Cancer Care, Inc. at 800-813-4673 or speak with an oncology social worker or cancer care liaison. Application materials are available at most Scripps Cancer Center sites.

Cancer Care partners with Avon Foundation and Komen Breast Cancer Foundation to offer the following programs for breast cancer patients:

- **AVON***Cares*: Limited financial assistance for homecare, childcare and transportation. A program in partnership with the Avon Foundation.
- Linking A.R.M.S.: Limited financial assistance for hormonal and oral chemotherapy, pain and anti-nausea medication, lymphedema supplies and durable medical equipment. A program in partnership with the Susan G. Komen Breast Cancer Foundation.
- The Colorectal CareLine Financial Aid Fund provides financial assistance through a small grant program for colorectal patients in need of debt crisis assistance. Financial assistance in the amount of \$200.00 is available to colorectal cancer patients with specific treatment related expenses and a family income less than \$75,000.00 annually. Patients must provide a verification of diagnosis and income as well as a documented need for financial assistance. Small grants are available for:
 - Temporary housing assistance as a result of treatment
 - Reimbursement for transportation to and from treatment
 - Childcare necessitated by treatment
 - Food costs incurred as a result of out of town treatment

Applications are completed by a Colorectal CareLine Financial Aid Fund Counselor via telephone. The program accepts calls Monday-Friday from 8:30 AM EST to 5:00 PM EST and can be reached at 1-866-657-8634. Website is www.colorectalcareline.org.

- Cancer Angels of San Diego is a local non-profit organization that provides funds to help needy San Diegans who have a stage IV cancer diagnosis. Funds can be used for rent, utilities, transportation, insurance and other expenses. Call 760-942-6346 or go to www.cancerangelsofsandiego.org.
- **The Bone Marrow Foundation** offers financial assistance to needy blood and marrow transplant recipients and their families. Call 800-365-1336 or see www.bonemarrow.org.

- The National Marrow Donor Program's Office of Patient Advocacy offers several patient assistance programs for BMT patients. Call 888-999-6743 or go to www.marrow.org/patient.
- The **Patient Advocate Foundation** maintains a comprehensive on-line list of assistance programs in their **National Underinsured Resource Directory**. Go to: https://patientadvocate.help4u.com/PAF/PAF_Home.aspx
- The Brenda Mehling Cancer Fund, based in Valencia, CA, helps patients 18 40 years old meet basic expenses while undergoing cancer treatment. Typical requests are in the \$500 \$1,000 range and can be for insurance co-payments, housing, transportation, and other expenses. For info, see www.bmcf.net or email info@bmcf.net
- Cancer scholarship information can be found on the **FinAid** website. This site provides listings of scholarships for cancer patients, cancer survivors, children of a cancer patient or survivor, students who lost a parent to cancer, and students pursuing careers in cancer research. Go to: www.finaid.org/scholarships/cancer.phtmlinformation

Co-payment Assistance

- Info on **prescription drug patient assistance programs** offered by pharmaceutical companies can be found at www.phrma.org or by calling 800-762-4636. Also check www.needymeds.org and www.rxhelpforca.org.
- Leukemia and Lymphoma Society's Co-Payment Assistance Program is available to patients with multiple myeloma, Hodgkin's disease, non-Hodgkin's lymphoma, acute myelogenous leukemia and myelodysplastic syndromes. Financial criteria must be met. Call 877-557-2672 or see www..lls.org/copay for details. This is a national program.
- CancerCare Co-Payment Assistance Foundation is currently providing pharmacy copay assistance of up to \$10,000 to patients with breast, colorectal, head and neck, non-small cell lung cancer, renal and pancreatic cancers who meet specific criteria related to diagnosis, treatment and financial situation. Funds are targeted for insurance copayments on prescription medications for cancer therapy. Go to www.cancercarecopay.org or call 1-866-55-copay.
- The HealthWell Foundation provides assist to eligible patients to cover certain out-of-pocket health care costs, including: prescription drug co-payments and deductibles, and health insurance premiums. See www.healthwellfoundation.org or call 800-675-8416.
- The Patient Advocate Foundation's Patient Assistance Program provides financial assistance to help patients pay for necessary prescriptions and/or treatment co-payments

not covered by insurance. Financial and disease eligibility criteria must be met. See www.copays.org or call toll free 866-512-3861 for details and list of covered diseases. PAF also has a special **Colorectal Careline** Financial Aid Fund. See www.colorectalcareline.org or call 866-657-8634. The homepage for PAF is www.panfoundation.org. This non-profit organization is based in Newport News, VA.

- Patient Access Network Foundation provides financial assistance to patients who can't afford the out-of-pocket costs associated with their treatment needs. Drug costs are included. Financial and disease eligibility criteria must be met. Only a limited number of conditions are covered. See www.patientaccessnetwork.org or call 1-866-316-7263. Website has list of covered conditions and covered medications.
- Patient Services Incorporated (PSI), based in Virginia, is a non-profit organization dedicated to providing health insurance premium assistance (including COBRA and MRMIP), and pharmacy co-payment assistance to needy families facing certain expensive chronic illnesses. CML, cancer with bone metastasis, and chemo-induced anemia or neutropenia are currently on their list of eligible conditions. Conditions are added and deleted depending on available funding. Call 800-366-7741 for details. See www.uneedpsi.org.
- The Partnership for Prescription Assistance connects low-income, uninsured or underinsured patients to prescription assistance programs, many of which provide medicines for free or nearly free. The website offers access to numerous public and private patient assistance programs. See www.pparx.org or call 1-888-477-2669.
- The Chronic Disease Fund, based in Texas, provides co-pay assistance to under-insured patients who require the use of expensive, specialty therapeutics. The fund currently assists patients with breast, liver and pancreatic cancer, multiple myeloma and myelodysplastic syndrome. See www.cdfund.org or call 877-968-7233 for current list of covered diseases and medications.

SDG&E Residential Rate Assistance Programs

SDG&E has two residential rate assistance programs: California Alternate Rates for Energy (CARE) and Family Electric Rate Assistance (FERA). Both programs are based on total household income and household size. The CARE program provides a 20% discount on monthly gas and electric bills for qualifying households. For households with three or more persons, the FERA program provides a discount on electricity costs once the home energy usage reaches a certain level. For more information call 800-411-7343, or go to www.sdge.com/residential and click on "assistance services".

All About COBRA: Continuing Your Health Insurance if You Leave Your Job

The Consolidated Omnibus Budget Reconciliation Act (COBRA) was passed in 1986 allowing terminated employees, or those who lose coverage because of reduced work hours, to buy group health insurance (but not life insurance) for themselves and their families for limited periods of time. For cancer survivors and their families, it is important to know what COBRA is and the benefits it offers.

According to COBRA if your employer has, or has had, more than 20 employees for at least 50% of last year, then you and your covered dependents are entitled to a continuation of your group health insurance benefits if your employment is voluntarily or involuntarily terminated (other than for gross misconduct) or your hours are reduced. Under these circumstances you and your covered dependents can be allowed to continue coverage for up to 18 months. If you or a covered dependent is determined to be disabled for Social Security purposes at the time of either of the above, then you can continue coverage for a total of 29 months, until Medicare eligibility is reached. Under some circumstance, depending on the qualifying event, coverage can be extended to 36 months. You need to notify your employer when you become eligible for Social Security Disability and ask about a COBRA extension. In addition to the above, your spouse may qualify for COBRA if you become entitled to Medicare, are divorced or legally separated, or if you die. However, COBRA does not apply to plans sponsored by the Federal government and certain church-related organizations.

If you are entitled to COBRA benefits, your health plan must give you a notice stating your right to choose to continue benefits provided by the plan. You have 60 days to accept coverage or lose all rights to benefits. **Be sure to meet all deadlines for applying and paying premiums**. **If deadlines are missed, benefits will be denied.**

Once COBRA coverage is initiated, your employer does not have to pay part of your insurance coverage any longer. Therefore, the full premium for your coverage will be due, plus 2% for administrative costs. The premium will be higher if you continue your benefits due to a disability. However, coverage under any group plan is usually much less expensive than individual coverage.

COBRA coverage begins the day your previous coverage would have otherwise been lost. It will be discontinued on the last day maximum coverage is reached or if:

- you become covered under another group plan or are eligible for coverage under Medicare. If, however, the new group plan has a waiting period for pre-existing conditions, you may keep your COBRA coverage for that time frame;
- the covered person fails to pay the premium for coverage;
- the employer ceases to provide any group health plan.

In addition, a spouse who is legally separated or divorced from the covered employee will lose their coverage the day he/she is remarried and becomes covered under a group health plan.

COBRA offers some very important benefits for cancer survivors, but it is important to remember that the coverage is not inexpensive. Remember, if you are interested in COBRA coverage, you must notify your employer within 60 days of the receipt of the notice.

In 1998, a new state law took effect which created a state COBRA program called CAL-COBRA for employees of businesses with between two and 19 employees. This program provides coverage that lasts up to 36 months, depending on the qualifying event. This legislation also makes it possible for individuals to obtain "guaranteed issue" coverage *after* COBRA runs out. For more information about COBRA, speak with your employer's human resources department, or contact a reputable insurance professional.

- ✓ A knowledgeable local source of information and guidance regarding COBRA, HIPAA and MRMIP is insurance expert, **John J. Rodee**, **CLU**, **619-298-5177** (Mission Valley)
- More info about COBRA can be found online at the Department of Labor's website. See: www.dol.gov/dol/topic/health-plans/cobra.htm or at www.insurance.ca.gov (California Department of Insurance). Another informative website about COBRA and California disability benefits is the Disability 101 site: www.disabilitybenefits101.org.

<u>The Health Insurance Portability</u> <u>and Accountability Act</u>

The "HIPAA" law passed by Congress in August 1996, makes it much easier for most people to get and keep health insurance. The law, also called the Kennedy-Kassebaum act after its leading sponsors, took effect in California in January of 1998. In general, the law affects people who receive health insurance from their employer, either as beneficiaries of employer-operated plans or members of a group policy purchased from an insurance company. The law only covers persons enrolled in, or eligible for, one of these forms of group coverage. The Kennedy-Kassebaum act prevents group health plans from denying coverage to applicants, including their dependents, because of past or present health problems or claims history. Insurers cannot reject applicants because of their genetic makeup – a key provision for cancer survivors and people genetically at risk for developing cancer.

Congress understood that cancer survivors and many others were afraid to change jobs for fear of losing their coverage altogether, or of losing coverage for a pre-existing condition. The new law addresses the latter problem by assuring that when a person changes from one group plan to another, even a pre-existing condition will be covered after 12 months of continuous coverage. (Pre-existing conditions are medical conditions for which medical advice, diagnosis, or treatment was received or recommended within the previous six months.)

For more info about HIPAA go to the website of the U.S. Department of Labor (ww.dol.gov/ebsa/) and type in HIPAA in the search window.

The Family and Medical Leave Act

The Family and Medical Leave Act requires employers with 50 or more employees to provide up to 12 weeks of unpaid, job-protected leave for family members who need time off to address their own serious illness or in order to care for a seriously ill child, parent, spouse, or a healthy newborn or newly adopted child. An employee must have worked at least 25 hours per week for one year to be covered. The law allows companies to exempt their highest paid workers. Employees may enforce their rights by filing a lawsuit within two years of any alleged discrimination.

The Family and Medical Leave Act:

- a. provides 12 weeks of unpaid leave during any 12 month period;
- b. requires employers to continue to provide benefits including health insurance during the leave period;
- c. requires employers to restore employees to the same or equivalent position at the end of the leave period;
- d. allows leave to care for a spouse, child, or parent who has a "serious" health condition";
- e. allows leave because a serious health condition renders the employee "unable to perform the functions of the position";
- f. allows intermittent or reduced work schedule when "medically necessary" (under some circumstances an employer may transfer the employee to a position with equivalent pay and benefits to accommodate the new work schedule";
- g. requires employees to make reasonable efforts to schedule foreseeable medical care so as to not disrupt unduly the workplace;
- h. requires employees to give employers 30 days notice of foreseeable medical leave or as much notice as is practicable;
- i. allows employers to require employees to provide certification of medical needs and allows employers to seek a second opinion (at employer's expense) to corroborate medical need;
- j. permits employers to provide leave provisions more generous than those required by the Family and Medical Leave Act; and
- k. allows employees to "stack" leave under the Family and Medical Leave Act with leave allowable under state medical leave law.

From Working It Out: Your Employment Rights As a Cancer Survivor, NCCS, 1995.

<u>Paid Family Leave Insurance</u>

Most Californians are eligible to receive up to six weeks of **Paid Family Leave Insurance** benefits over a 12-month period. Any employee who contributes to the State Disability Insurance program (SDI) and must care for an ill child, spouse, parent or domestic

partner may be eligible for benefits. SDI provides partial wage replacement to eligible workers – approximately 55% of normal wages. For 2005, weekly benefits range from \$50 to \$840. Paid Family Leave does not provide job protection or return rights. Your job may be protected if your employer is subject to the federal Family Medical Leave Act and the California Family Rights Act. Speak with your Human Resources department for more information. On the internet, go to www.edd.ca.gov and click on Paid Family Leave under "Top Links". There is lots of info in the "FAQ" section. Paid Family Leave is a component of the State Disability Insurance Program and is administered by the Employment Development Department of the State of California.

Income Tax Deductions for Medical Expenses

Even with good medical insurance, out-of-pocket expenses for treatment and follow-up care can be significant. One way to potentially recoup a portion of these expenses is to file an itemized deduction of your medical expenses on your federal tax return. By keeping track of expenses and by deducting qualified items, you may be able to partially recover some of your medical expenses not covered by your insurance.

"The 7.5% Rule" is the key to determining whether or not you are able to take advantage of this tax deduction. The rule stipulates that you are only allowed to deduct the amount of your medical and dental expenses that is greater than 7.5% of your adjusted gross income. If your income is high or your expenses are low, you may not be able to use this deduction. For more information on deducting medical and dental expenses from your income taxes, see Publication 502 and the instructions for Schedule A of Form 1040 at www.irs.gov. An experienced tax advisor is the best source of guidance regarding your specific tax situation.

Wigs and Hair Accessories



Many local wig shops and hair salons have experience helping people suffering from chemotherapy or radiation therapy-induced hair loss. Some insurance companies cover a portion of the cost of a wig if it is purchased as a result of hair loss from cancer treatment. The wig is viewed as a prosthetic device that is part of the rehabilitation process. Check with your insurance company regarding coverage. Medicare unfortunately does not reimburse for

wig purchases. Some Scripps contracted insurance plans with wig coverage require your physician to submit an authorization request. Your doctor's secretary can usually help with this. After the request is approved, you will need to purchase your wig from a contracted provider. Contact your insurance carrier for details.

One of the most common complaints about wigs is that they can be hot and they can cause the scalp to itch. Fortunately, there are products available today to relieve or minimize such reactions. There are, of course, options to wigs. Many women experiencing hair loss also use headwraps, hats and scarves.

An assortment of free wigs, caps, and hair accessories are usually available from the Scripps Cancer Center. Contact the appropriate SCC social worker or cancer care liaison (see phone numbers at end of Directory) to determine what items are currently available.

- A fine book on makeup techniques for women undergoing cancer treatment is *Facing the Mirror with Cancer: A guide to using makeup to make a difference*. The book was written by Laurie Ovitz who has worked for 20 years as a respected makeup artist in Chicago. See www.facingthemirror.org for details. A copy of the book should be available for review at one or more Scripps Cancer Center sites.
- ✓ The American Cancer Society sponsored *Look Good...Feel Better* program is offered regularly at various locations throughout San Diego County, including several Scripps sites. In this free evening program, licensed cosmeticians provide valuable information and demonstrations on makeup, skin care, wigs and accessories. Call ACS at 619-299-4200 for more information.
- ✓ Free new wigs are available at the American Cancer Society **Discovery Shop** at 3609 Midway Drive, San Diego. Call 619-224-4336 for information.
- ✓ **Locks of Love** is a non-profit organization based in Florida that provides hairpieces to financially disadvantaged children under age 18 suffering from long-term medical hair loss, usually alopecia areata. Locks of Love accepts donations of hair, 10" minimum. See www.locksoflove.com or call 888-896-1588 for more information.

Homecare and Medical Equipment



In recent years there has been a gradual shift of care from the hospital setting to the out-patient setting. This shift has resulted in a steady growth in the availability and scope of home care services – services that allow the patient to recuperate and sometimes receive treatment in the comfort of their own home. Homecare generally refers to services provided by registered nurses; physical, occupational and speech therapists; social workers and home health aides.

What does insurance cover? Most insurance pays for intermittent "skilled" homecare when prescribed by a physician. Skilled care refers to services provided by a registered nurse, physical therapist, or speech therapist and usually involves brief visits to treat specific medical concerns.

Many people who require homecare primarily need help with personal care or "custodial care". Custodial care refers to help with walking, bathing, dressing, eating and other activities of daily living or "ADLs". A nurse's aide provides this level of assistance. Many insurance plans have homecare benefits that are similar to the Medicare homecare benefit which will pay for brief nurse's aide visits 2 to 3 times a week, but only as long as there is also a need for regular visits by one of the skilled specialists (RN, physical therapy, etc.). If there are no documented skilled needs, there is usually no coverage for personal care alone. The need for more comprehensive coverage for personal care at home has created a market in the insurance industry for special long-term care policies that fill the gaps in homecare benefits that exist under Medicare and most other plans. Hourly help from nurse's aides can be obtained from homecare agencies. These agencies are listed in the Yellow Pages under "Home Health Services". Agency rates for nurse's aides in San Diego County are currently in the \$16 to \$22 an hour range. Most agencies have a four-hour minimum, but some are more flexible regarding minimum hours. Live-in help through home health agencies now runs around \$160 to \$225 a day.

Aides who work for agencies usually have received basic training leading to certification. There are two types of aides: certified nurse's assistants (CNAs) and certified home health aides (CHHAs). CHHAs have had slightly more training than CNAs.

Most insurance plans include coverage for medical equipment, such as walkers, commodes and hospital beds; however items for the bathroom, such as grab-bars or shower chairs, are usually not covered. Eligibility criteria for medical equipment must be met and a physician's prescription is generally required. With HMO type plans the physician must first submit an "authorization request" to the insurance carrier or intermediary. After the authorization is approved, arrangements for homecare or equipment delivery are made with contracted homecare or medical equipment providers. Don't purchase equipment first and then try to get reimbursed – this can be difficult. For more information about homecare or medical equipment resources, speak with a hospital social worker, discharge planner or cancer care liaison.

✓ Scripps Home Health Care (800-522-1192) offers skilled homecare services to the greater San Diego community.

Services for Seniors

- Some seniors organizations maintain listings of homemakers and aides who work privately. These individuals are not affiliated with homecare agencies and are not supervised. You hire and negotiate rates and you may be responsible for proper tax withholding for the IRS. Check with senior centers located near you. These organizations often also have information about shared housing, transportation, case management and home modification programs.
- ✓ Info regarding homecare, medical equipment, and a wide range of services for seniors can be found on the **San Diego Network of Care** website, which was created by the S. D. County Department of Aging and Independent Services with a grant from the California Department of Aging. See http://sandiego.networkofcare.org/aging/home/index.cfm. Another valuable internet resource is the **San Diego Eldercare Directory**, available online at http://eldercare.uniontrib.com.
- ✓ The San Diego County Department of Aging and Independence Services (858-495-5069) is an excellent source of information regarding senior services. They offer a wide range of programs for seniors and disabled San Diegans. On the web go to: www.sdcounty.ca.gov/hhsa/programs/ais/.
- ✓ ElderHelp of San Diego provides a series of valuable programs for older adults in San Diego, including case management, info and referral, homesharing, benefits counseling and minor home repairs. Their Seniors a Go Go program provides transportation within a 15 mile radius of home. Service area is based in Central San Diego. Their main office is in North Park: 619-284-9281. On the web: www.elderhelpofsandiego.org.

Hospice Care

Hospice is a program of care designed to maximize the quality of life for people in the final stages of a terminal illness, and to provide support and guidance to caregivers. Care is usually provided in the patient's home, but hospice staff can also follow patients in hospitals, nursing homes, and in some retirement homes. Hospice organizations are similar to homecare agencies, however hospices work solely with people who have limited life expectancies. Hospices also have a unique philosophy of care and a special team approach.

Hospices provide physical, emotional and spiritual care through the efforts of a team that is lead by the hospice nurse (a Registered Nurse) who visits the home on a regular basis -- one to three times a week, or more often if necessary. Visits usually last around an hour. The nurse assesses the patient's physical condition, provides nursing care, and teaches the patient and caregiver effective techniques for managing the patient's personal care. Comfort, safety, and dignity are a top priority. The hospice RN communicates closely with the patient's physician who continues to remain actively involved.

In addition to the hospice nurse, a number of other hospice team members can be called upon for support, including home health aides, social workers, chaplains, and volunteers. The Medicare hospice benefit and hospice benefits under other plans usually cover brief nurse's aide visits several times a week, primarily for bathing. If additional help is required, it usually must be paid for privately. Hospice benefits under different insurance plans vary, but they always pay for intermittent rather than comprehensive services. Eight hours a day of care at home, for instance, is generally not a covered service. Under rare circumstances, however, Medicare and other providers may sometimes pay for 24-hour short-term continuous care at home to prevent a hospitalization that the patient and family would prefer to avoid.

Eligibility for hospice care is dependent upon insurance criteria that are generally modeled after criteria in the Medicare hospice benefit. To be eligible for hospice under Medicare, a patient's life expectancy in the physician's judgement should be in the six months or less range. This is, of course, always a rough estimate.

A second important criterion is that the goal of the patient's treatment is "palliative" rather than "curative" in nature. Palliative care focuses on comfort and symptom management. Hospice criteria represent general guidelines: hospice teams assess each case individually. For instance, patients generally don't receive chemotherapy or radiation therapy while on hospice. If the goal of the treatment is solely to control symptoms, however, a cycle of chemo or radiation therapy may be appropriate for a patient who is being followed by hospice.

For hospice services to be initiated there must first be an order from a physician. When a referral is sent to a hospice, a hospice representative confirms insurance coverage and then calls the patient or family to arrange a time for a hospice evaluation visit. If the patient and family decide to be followed by hospice, paperwork is signed and a preliminary care plan is formulated. If, after signing on with hospice, a patient decides to discontinue services for any reason, this can easily be accomplished. Occasionally a patient's condition improves to the point where hospice support is no longer required and services are stopped. If needs arise at a later date, hospice services can be reinstated.

National Hospice Organization

703-243-590,

Helpline: 800-658-8898

1901 North Moore St., Ste. 901, Arlington, VA 22209 www.nhpco.org

NHO, founded in 1978, is a non-profit association dedicated to promoting and maintaining quality care for terminally ill people and their families. It provides educational programs, technical assistance, publications, and advocacy and referral services. Website has a valuable "Find a Provider" section that lists hospices across the United States.

- To discuss your personal situation and learn more about how hospice may benefit you and your family, speak with a Scripps Cancer Center social worker or cancer care liaison, or ask to have a hospice representative contact you by phone or meet with you in your home.
- For an interesting overview of hospice history in the United States see the **Hospice Association of America** timeline at http://www.nahc.org/HAA/history.html.
- ✓ All local hospices offer bereavement services and info regarding local bereavement resources. **The Center for Grief Care and Education** at San Diego Hospice offers an impressive array of bereavement groups and educational classes. Call 619-278-6480 for details or go to www.sdhospice.org.



The San Diego Eye Bank, one of the largest eye banks in the U.S., depends on the generosity of individuals and families who make the anatomical gift of eyes and corneas upon death. If you want to make a difference in someone's life who is cornea blind or who suffers from a blinding eye disease, tell your family you want to be an eye donor. Consent forms and more info is available from the S.D. Eye Bank, 800-393-2265 or www.sdeb.org.

Durable Power of Attorney for

Health Care

What is a Durable Power of Attorney for Health Care (DPAHC)?

The DPHC is a type of Advance Health Care Directive. Under California law, it allows you to name someone to make health care decisions for you if you are ever unable to make decisions for yourself as a result of your medical condition. By completing a DPAHC document, available in all Scripps hospitals or from a Scripps social worker or Cancer Care Liaison, you can appoint another person to be your health care "agent". That person will have legal authority to make most medical decisions regarding your care if you are ever in a position where you are unable to participate in the decision making process. You can also use the form to indicate when you would and wouldn't want particular kinds of treatments. Your agent must follow these instructions. A properly completed DPAHC provides the best assurance that your wishes will be respected if you become seriously ill and cannot speak for yourself.

Who can complete a DPAHC?

Any California resident who is at least eighteen years old, of sound mind, and acting on his or her own free will can complete a valid DPAHC. You do not need a lawyer to fill out the document.

Who can I appoint as my health care agent?

You can appoint almost any adult to be your agent. You can choose a member of your family such as your spouse or an adult child, a friend, or someone else you trust. You can also appoint one or more "alternate agents" in case the person you select as your health care agent is unavailable or unwilling to make a decision.

How does this person know what I would want?

After you choose someone, talk to that person about what you want. You can also write down in your advance health care directive when you would or wouldn't want medical treatment. Sometimes treatment decisions are hard to make and it truly helps your family and your doctors if they know what you want. The advance directive also gives these people legal protection when they follow your wishes.

How long is the DPAHC valid?

A DPAHC is valid for an indefinite period of time unless you state in the document a specific date when you want it to expire, or if the printed language in the form mentions a specific duration of time that the document will be valid. You can change or revoke this document any time as long as you can communicate your wishes.

What should I do with the DPAHC form after I fill it out?

Make sure that the form has been properly signed, dated, and either notarized or witnessed by two qualified individuals (the form includes instructions on who can and cannot be a witness). Keep the original in a safe place and give copies of the form to the persons you have appointed as your agent and alternate agent. Also give copies to your doctor and to anyone else who is likely to be called in the event of a medical emergency. In addition to providing your doctor with a copy it is important to tell your doctor about the wishes that you have expressed in the document. It is also a good idea to have a copy of the form inserted into your medical record if you are ever admitted to the hospital.

- ✓ **Durable Power of Attorney for Health Care** forms are usually available in hospitals or they can be obtained from hospital or cancer center support staff. This document can be downloaded from the publications page of the California Hospital Association website at www.calhospital.org/resource/advance-health-care-directive. Valid documents for all states can be downloaded from the National Hospice and Palliative Care Organization website: www.caringinfo.org. Click on "Planning Ahead" and look under the Advanced Directives heading.
- ✓ Cancer Legal Resource Center 866-843-2572, 213-736-1455
 www.disabilityrightslegalcenter.org/about/cancerlegalresource.cfm
 A joint program of the Western Law Center for Disability Rights and Loyola Law
 School. Free information and advice on legal issues relating to cancer in the workplace,
 insurance coverage, managed care/HMO's, trusts and estates, custody, guardianship,
 conservatorship, government benefits and advanced directives. Based in Los Angeles.
- ✓ Senior Citizens Legal Services provides free legal services to San Diego County senior citizens age 60 or older. Offices are located in San Diego, Oceanside, Chula Vista, El Cajon and El Centro. Call 858-565-1392 or see www.seniorlaw-sd.org. This program is one of several programs offered by Elder Law and Advocacy, funded by County of San Diego Aging and Independent Services. See HICAP (Health Insurance Counseling and Advocacy Program) in the "Insurance and Related Services" section of this directory.
- ✓ **Legal Aid Society of San Diego, Inc.** helps low income individuals with a wide range of legal concerns including will/estate planning, welfare and health benefits, and poverty law issues such as landlord/tenant disputes and disability support and family benefits payments. Federal Poverty Income Guidelines determine eligibility for free legal services. There are three offices in San Diego County. Call 877-534-2524 or go to www.lassd.org.

Cancer Center Phone Numbers

Scripps Cancer Center	Scripps Clinic and Scripps Green Hospital	
Cancer Special Services Program 858-554-8384 Paulette Geiger, RN Jane Williams, RN Hem-Onc Treatment Room 858-554-8593 Psychosocial Oncology Services Tom Friedman, LCSW, Oncology Social Worker 858-554-9376 Radiation Oncology 858-554-2000 Scripps Clinic Encinitas 760-753-5594 Scripps Clinic Rancho Bernardo 858-487-1800 Scripps Clinic Torrey Pines 858-455-9100 Scripps Green Hospital 858-455-9100 3 North (BMT Unit) 858-455-9100 Scripps Memorial Hospital Encinitas 760-633-6501 Cancer Care Liaison 760-633-7551 Scripps Memorial Hospital La Jolla 858-457-4123 Scripps Cancer Center 858-626-6756 7 West 858-626-6766 Radiation Oncology 858-626-6786 Oncology Social Worker 858-626-6786 Kelly McHenry, LCSW 858-349-2195 Clinical Coordinator/Nurse Navigator Janine Rodriguez, RN 858-626-7950 Scripps Mercy Hospital San Diego Campus 619-294-8111 Scripps Cancer Center 619-260-7280 <t< td=""><td>Scripps Cancer Center</td><td>858-554-8533</td></t<>	Scripps Cancer Center	858-554-8533
Paulette Geiger, RN Jane Williams, RN	Blood and Marrow Transplantation Program	858-554-2870
Jane Williams, RN Hem-Onc Treatment Room	Cancer Special Services Program	858-554-8384
Hem-Onc Treatment Room	Paulette Geiger, RN	
Psychosocial Oncology Services Tom Friedman, LCSW, Oncology Social Worker .858-554-9376 Radiation Oncology	· · · · · · · · · · · · · · · · · · ·	
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