# BREAST CARE RESOURCES

One of the most important ways to gain control over your disease and reduce your anxiety is to get answers to your questions. Because you are an individual, your questions and needs may be different from other women's. Your health care team at Southwestern Vermont Regional Cancer Center is your best source of information. In addition, there are many other sources of information and support. Most are available free of charge. Here are some tips and our most frequently recommended sources for more information.

### Tips for Getting Organized:

- Start a notebook for keeping information about your disease, treatment and recovery.
- Place these pages in your notebook.
- Write down your questions, and then read through the following list of resources for breast cancer patients.
- Call or email the resource. In your notebook, record your questions, the telephone number, when you called, and with whom you spoke.
- Print out information that you want to keep.
- Ask your healthcare team for the names of local sources of support or call your local hospital's library.

### Finding Information on the Internet

The Internet is a valuable resource, but be sure that the sites you visit are recognized as having sound clinical information. Most national cancer organizations have sites, as do many medical schools and universities. Internet access is available at most public and hospital libraries if you do not have a home computer with access.

### Suggestions for the Wisest Use of the Internet:

- Never substitute information found on the Internet for seeing or asking your healthcare provider about your concerns.
- Always seek information from reliable organizations and make sure that the information is dedicated to cancer education.
- Make sure the information is current. Look for the last update of the information on the site.

## GENERAL RESOURCES

**AMC Cancer Research Center's Cancer Information Line:** 1-800-525-3777 | **www.amc.org**
Professional cancer counselors provide answers to questions about cancer, support, and information on free publications. Equipped for deaf and hearing-impaired callers.

**American Cancer Society** (ACS)
1-800-ACS-2345 | 1-800-227-2345 | **www.cancer.org**
Provides free, written information on breast cancer, support group information, and referrals to Reach to Recovery program for peer interaction.

Southwestern Vermont
REGIONAL CANCER CENTER

**Association of Cancer Online Resources | 1-212-226-5525 | www.acor.org**
Online cancer information system that archives online support groups, information on treatments and clinical trials, links to other cancer education, advocacy groups on the Internet, and much more.

**BreastCancer.net | www.breastcancer.net |** Archives the latest news on breast cancer and allows quick and specific searches.

**BreastCancer.org | www.breastcancer.org |** Breast cancer education site including articles, news, newsletters, and chats.

**CancerIndex.org | www.cancerindex.org**
Online index of cancer resources and Web sites providing information and support. Provides a collection of media clips on various breast cancers. To access media clips, choose "Breast Cancer" from the list on the main screen, and then click on "Multimedia Breast Cancer Resources."

**Cancerlinks.org | www.cancerlinks.org |** A directory of other sites and resources on specific cancers.

**Chemocare.com | www.chemocare.com**
Web site designed to provide the latest information about chemotherapy side effects and self-care for patients, families, and caregivers. Regularly updated by Cleveland Clinics.

**Merck Manual Online Medical Library | www.merck.com/mmhe/index.html**
Explains disorders, their symptoms, how they are diagnosed, and how they can be treated. Based on the world's most widely used textbook of medicine, The Merck Manual, but written in everyday language for patients. Provided free of charge on the Internet by Merck & Co., Inc., as a public service.

**National Cancer Institute** (NCI) **|** 1-800-4-CANCER (1-800-422-6237)
**www.cancer.gov |** Comprehensive info on breast cancer news, diagnosis, treatment, statistics, research, and clinical trials.

## ADVOCACY GROUPS / ORGANIZATIONS

**Avon Breast Crusade | www.avoncrusade.com**
A fundraising effort that has raised over $585 million for breast cancer education and research in countries around the world.

**National Breast Cancer Coalition |** 1-202-296-7477 **| www.natlbcc.org**
Grassroots advocacy group of hundreds of member organizations and tens of thousands of individuals fighting breast cancer though action, advocacy, and public education.

**National Coalition for Cancer Survivorship |** 1-877-622-7937 **| www.canceradvocacy.org**
Advocates for quality cancer care for all Americans and the empowerment of cancer survivors through federal policy initiatives.

**Patient Advocate Foundation |** (Employment Issues) **|** 1-800-532-5274 **| www.patientadvocate.org**
The Patient Advocate Foundation is a national non-profit organization that serves as an active liaison between the patient and her insurer, employer, and/or debt holders in matters relative to a diagnosis through case managers, doctors, and attorneys. Patient Advocate Foundation seeks to safeguard patients through effective mediation, ensuring access to care, maintenance of employment, and preservation of financial stability.

**Susan G. Komen for the Cure |** 1-877-GO-KOMEN (1-877-465-6636) **| www.komen.org**
Offers information on all areas of breast cancer treatment and support.

## BREAST RECONSTRUCTION

**American Cancer Society | www.cancer.org |** Search: breast reconstruction
Breast reconstruction after mastectomy information.

**BreastCancer.org | www.breastcancer.org/pictures/treatment/**
Pictures of breast cancer patients with different types of breast reconstruction.

**Breast Implants |** 1-888-463-6332 **| www.fda.gov |** Search: breast implants
Information on choosing an implant, the associated risks, FDA regulations, and manufacturers of implants.

**Center for Microsurgical Breast Reconstruction | www.diepflap.com**
Explanations of DIEP and SGAP reconstruction procedures, timelines, and before-and-after photos.

**Medline Plus**
**www.nlm.nih.gov/medlineplus/breastreconstruction.html |** Complete guide to different types of breast reconstruction.

## COMPLEMENTARY AND ALTERNATIVE MEDICINE (CAM)

**Glycemic Index** | **www.southbeach-diet-plan.com/glycemicfoodchart.htm**
List of foods sorted by category shown on a scale from 0 to 100 based on the extent to which they raise blood sugar levels.

**Office of Dietary Supplements (ODS), NIH** | **www.ods.od.nih.gov**
Site offering research resources, frequently asked questions and fact sheets about supplements, all geared toward helping the public make informed decisions.

**National Council Against Health Fraud** | **www.ncahf.org**
Provides links to position papers and information about alternative and unproven treatments.

**U.S. Food and Drug Administration** (FDA) | **www.fda.gov/Food/default.htm**
Site for the Center for Food Safety and Applied Nutrition provides links to info on food safety, labeling, nutrition, and cosmetics.

## CANCER TREATMENT / CLINICAL ASPECTS

**Cancer.gov: Breast Cancer Clinical Trials** | **www.cancer.gov/clinicaltrials**
Information on choosing and participating in clinical trials, results of recent trials, and resources for finding a trial.

**Inflammatory Breast Cancer (IBC) Research Foundation** | **www.ibcresearch.org**
General information, research, articles, news articles, discussion, and commentary on inflammatory breast cancer.

**National Cancer Institute** | **www.cancer.gov**
The National Cancer Institute maintains a cancer treatment database providing prognostic, stage, and treatment information on more than 1,000 protocol (treatment) summaries.

**National Comprehensive Cancer Network: Breast Cancer Treatment Guidelines for Patients** | **www.nccn.org**
Decision trees included on this site aid patients in choosing treatment and follow-up options. Also available in Spanish.

## CHILDREN AND FAMILIES

**Caring Bridge** | **www.caringbridge.org**
Non-profit Web service that provides a free Web site to anyone going through a health crisis, treatment, or recovery.

**Kids Konnected** | 1-800-899-2866 | **www.kidskonnected.org**
Kids Konnected is a non-profit organization that provides for the needs of the children of cancer patients. They offer a kid-friendly and informative Web site, a 24-hour hotline, leadership training, support groups, online forums, a teddy bear outreach program, and other support tools for children and families.

## EMPLOYMENT CONCERNS

**American Cancer Society - Americans With Disabilities Act** | **http://www.cancer.org/docroot/MIT/mit_3_1_2.asp**
Provides basic information about the Americans with Disabilities Act.

**Family and Medical Leave Act** | 1-866-4 US WAGE (1-866-487-9243) | **http://www.dol.gov** | Search: FMLA
Web site includes a fact sheet about FMLA. The toll-free number reaches the Wage and Hour Division at the Department of Labor. They can tell you how to reach the division office nearest you.

**National Coalition for Cancer Survivorship (NCCS) Employment**
**http://www.canceradvocacy.org/resources/employment.html**
NCCS offers valuable information on your employment rights as a cancer survivor, including a free download of their publication Working It Out.

**The US Equal Employment Opportunity Commission** | **http://www.eeoc.gov/facts/cancer.html**
Includes frequently asked questions about cancer in the workplace and patients', and survivors', rights under the Americans with Disabilities Act.

## HAIR CARE AND MAKE-UP

**Look Good ... Feel Better** | 1-800-395-LOOK (5665) | **www.lookgoodfeelbetter.org**
A comprehensive online guide to caring for your hair and skin during cancer treatment. Contact your local American Cancer Society for free classes and instructions on make-up application and hair care during treatment.

**Cancer.Net**

**http://www.cancer.net/patient/Library/Financial+Resources**
List of financial resources available through local and national service organizations for travel and housing assistance, medication and treatment cost assistance, and general financial information.

**Georgetown University Health Policy Institute**

**http://www.healthinsuranceinfo.net**
The Health Policy Institute has prepared a consumer guide for getting and keeping health insurance for each state and the District of Columbia. The guides are accessible for printing or viewing online.

**National Coalition for Cancer Survivorship (NCCS) Insurance**

**http://www.canceradvocacy.org/resources/insurance.html**
NCCS offers tips about getting, keeping and affording health insurance, including a free download of their publication *What Cancer Survivors Need to Know About Health Insurance.*

## LYMPHEDEMA

**National Lymphedema Network** | 1-800-541-3259 | **www.lymphnet.org**
Provides education and guidance to lymphedema patients, health care professionals, and the general public.

## MALE BREAST CANCER

**ACS: Male Breast Cancer Resource Center** | **www.cancer.org** | Search: male breast cancer
Information and links to other Web sites on male breast cancer.

**MedicineNet.com** | **www.medicinenet.com/male_breast_cancer/article.htm**
Provides online education about diagnosis and treatment of male breast cancer.

**YourShoes® at Network of Strength** | 1-800-221-2141 | **www.networkofstrength.org**
The 24-hour YourShoes Support Center can provide you with information about male breast cancer and help address your concerns. Through the Match Program, you can be put in touch with a man who has survived male breast cancer.

## PREGNANCY AND BREAST CANCER

**Breast Cancer.org** | **www.breastcancer.org/tips/fert_preg_adopt/bc_pregnancy**
Discussion of decisions about treatment during pregnancy.

**Fertile Hope** | **www.fertilehope.org**
Fertile Hope is a national non-profit organization dedicated to providing reproductive information, support, and hope to cancer patients whose medical treatments present the risk of infertility.

**Hope for Two: Pregnant With Cancer Network** | 1-800-743-4471 | **www.pregnantwithcancer.org**
Connects pregnant women diagnosed with cancer to women who have lived through the experience.

## PROSTHESIS

Check in the yellow pages of your telephone book, call your local unit of the American Cancer Society or ask your surgeon or nurse for references.

**Network of Strength (Formerly Y-Me)** | 1-800-221-2141 (24-hr English hotline) | 1-800-986-9505 (24-hr Spanish hotline)
**www.networkofstrength.org**
A wig and prosthesis program is available free to women who cannot afford to purchase these items.

**ReForma** | **http://myreforma.com**
Reusable, hypoallergenic and self-adhering prosthetic nipples available in two sizes and three colors.

**Softee** | 1-866-605-8585 | **www.softeeusa.com**
Site offering a wide selection of post-surgical products for recovery, including reconstruction camisoles.

## SEXUALITY

**International Academy of Compounding Pharmacies** | 1-800-927-4227 | **www.iacprx.org**
Allows patients to search for a local compounding pharmacist.

**Pure Romance** | 1-866-ROMANCE | **www.pureromance.com**
Offers a range of intimate products, in-home parties, and the Sensuality, Sexuality, Survival (SSS) program, which serves as a resource for women surviving cancer who have questions about renewing their intimacy.

## SUPPORT GROUPS / ORGANIZATIONS

**African-American Breast Cancer Alliance (AABCA)** | 1-800-ACS-2345 | **www.geocities.com/aabcainc**
This organization provides education to African-American women on breast health, early detection, and breast cancer support groups. For more info and to see if there is an alliance in your area, call the ACS at 1-800-ACS-2345.

**Breast Cancer Network of Strength** | 1-800-221-2141 (24 Hour Hotline-English) | 1-800-986-9505 (24 Hr Hotline-Spanish)
**www.networkofstrength.org**
Provides support and counseling through their 24-hour hotline YourShoes. Trained volunteers, all of whom have had breast cancer, are matched by background and experience to callers whenever possible. Interpreters are available in 150 languages. Referrals for major cancer treatment centers are also available.

**Cancer Care, Inc.** | 1-800-813-HOPE (1-800-813-4673 | **www.cancercare.org**
Offers free assistance to cancer patients through counseling, education, referral, and direct financial assistance.

**Living Beyond Breast Cancer** | 1-888-753-5222 | **www.lbbc.org**
Provides interactive conferences, teleconferences, a toll-free information and support line, free newsletters and publications, low-cost informational recordings, and a networking program.

**Local Support Groups**
Call your local American Cancer Society office for local support group meetings. Local numbers may be acquired by calling the national office at 1-800-ACS-2345. Or call your local cancer treatment center for support group information.

**National Asian Women's Heath Organization** (NAWHO) | **www.nawho.org**
The site explains the organization's program, Communicating Across Boundaries: The Asian American Woman's Breast and Cervical Cancer Program, and offers a free download on related cultural competency training.

**National Coalition for Cancer Survivorship** (NCCS) | 1-877-NCCS-YES (1-877-622-7937 | **www.canceradvocacy.org**
Survivorship info and support. The Cancer Survival Toolbox, a CD of survival skills, is provided free (also available in Spanish).

**Pink-Link** | **www.pink-link.org**
A free online breast cancer support network with access to a member forum, online journals, and breast cancer resources.

**SHARE: Self Help for Women With Breast or Ovarian Cancer** | 1-866-891-2392 | **www.sharecancersupport.org**
Offers survivor-led support to women with breast or ovarian cancer, their families, and friends. Services include hotlines, survivor-led support groups, wellness programs, educational forums, and advocacy activities.

**Sharsheret** (Jewish Women) | 1-866-474-2774 | **www.sharsheret.org**
Provides support and resources for young Jewish women facing breast cancer. Offers a peer support network connecting young women with others who share similar diagnoses and experiences, as well as education and outreach programs.

**Sisters Network Inc.** (African-American Women) | 1-866-781-1808 | **www.sistersnetworkinc.org**
African-American breast cancer survivorship organization. Promotes the importance of breast health through empowerment, support, breast education programs, resources, information, and research.

**The Wellness Community** | Phone: 1-202-659-9709 Fax: 1-202-659-9301 | **www.thewellnesscommunity.org**
The Wellness Community is a national non-profit organization dedicated to providing free emotional support, education and hope for people with cancer. There are 20 facilities nationwide. The Web site offers online support groups and an online newsletter for cancer patients.

**Yes, I Can Action Now** | **www.yesicannow.org**
"Yes, I Can Now" is a program created by Aventis Oncology for women with breast cancer. It is a web- and mail-based program providing patients with survivor stories, diet and exercise tips, medical information, treatment organizers, and other valuable information. Patients can go online to sign up.

**The Young Survival Coalition (Young Women)** | 1-877-972-1011 | **www.youngsurvival.org**
An advocacy and awareness organization for young women who are diagnosed with breast cancer. The group offers support, information, and education.

## SURGERY

**Breast Cancer Network of Strength** | 1-800-221-2141 (24-hr Hotline-English) | 1-800-986-9505 (24-hr Hotline-Spanish)
**www.networkofstrength.org**
Gives referrals to major cancer treatment centers for second opinions or treatments not offered in some localities.

**Caring Connections** | **www.caringinfo.org/stateaddownload**
Caring Connections provides free advance directives and instructions for each state that can be opened as a PDF file.

## SURVIVORSHIP MAGAZINES

***Breast Cancer Wellness Magazine*** | **www.breastcancerwellness.org**
Mission of magazine is to empower mind, body and spirit of women diagnosed with breast cancer. Go online for a free subscription.

***Coping With Cancer*** | 1-615-790-2400 | **www.copingmag.com**
*Coping with Cancer* is America;s consumer magazine for people whose lives have been touched by cancer. For a subscription go online or call.

***CURE*** | 1-800-210-CURE (2873) | **www.curetoday.com**
*CURE* is a magazine for cancer patients and their families, providing information on recent advancements in diagnosis, treatment and prevention of cancer. Healthcare providers and patients can go online to sign up for a free subscription.

***MAMM*** | 646-365-1350 | **www.mamm.com**
*MAMM* is a magazine devoted to women diagnosed with breast and reproductive cancer. For a subscription go online or call.

## SURVIVORSHIP RESOURCES

**Imaginis** | **www.imaginis.com**
Web site providing education and the latest news in breast cancer for professionals and patients. Sign up for the online newsletter to receive concise summaries on the latest news and information on breast cancer.

**Reach To Recovery** | National ACS Office 1-800-ACS-2345 | **www.cancer.org**
This program of the American Cancer Society offers in-home visits from volunteers. Call your local ACS unit for an appointment. Volunteers will share helpful information for recovery, including range of motion exercises for the surgical arm.

**Survivorship A-Z: Practical Information for Living Successfully After a Diagnosis** | **http://www.survivorshipatoz.org**
Survivorship A-Z provides practical information survivors need to thrive in the "new normal" that exists after a life-changing diagnosis.