



Resources

There are many good resources for people with breast cancer. We do not try to include them all. The groups in this list are those we refer to in the guide.

Helpful Organizations	Why We Recommend Them
<p>NATIONAL BREAST CANCER COALITION/FUND (NBCC/F) 1707 L Street, NW, Suite 1060 Washington, DC 20036 Tel: (800) 622-2838 (202) 296-7477 Fax: (202) 265-6854 www.stopbreastcancer.org</p>	<ul style="list-style-type: none"> • To get more copies of this guide, • To find one of our field coordinators in your area, • For our paper called, “Criteria to Evaluate Quality Clinical Trials,” • For our position statement on “Medical Privacy,” • For our position statement on “Genetic Testing,” • For our position statement on “High-Dose Chemotherapy with Bone Marrow Transplant or Stem Cell Support,” and • To get involved in breast cancer advocacy and NBCCF’s programs.
<p>AMERICAN BAR ASSOCIATION’S COMMISSION ON WOMEN IN THE PROFESSION 750 N. Lakeshore Drive Chicago, IL 60611 Tel: (312) 988-5715 Fax: (312) 988-5688 www.abanet.org/women/home.htm</p>	<ul style="list-style-type: none"> • To find free legal help in your area.
<p>AMERICAN CANCER SOCIETY (ACS) National Home Office 1599 Clifton Road, NE Atlanta, GA 30329-4251 Tel: (800) ACS-2345 www.cancer.org</p>	<ul style="list-style-type: none"> • For evidence-based information on complementary and alternative medicine.

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<p>AMERICAN SOCIETY OF CLINICAL ONCOLOGY (ASCO) 1900 Duke Street, Suite 200 Alexandria, VA 22314 Tel: (703) 299-0150 Fax: (703) 299-1044 www.asco.org</p>	<ul style="list-style-type: none"> • To find oncologists that are Board-certified.
<p>AVON BREAST CANCER CRUSADE Avon Breast Care Fund 505 Eighth Avenue, 16th floor New York, NY 10018-6505 Tel: (212) 244-5368 Fax: (212) 695-3081 www.avonbreastcare.org</p>	<ul style="list-style-type: none"> • To find a group in your area that provides free or low-cost mammograms to women without health insurance. Avon funds many groups to provide this service.
<p>BLUE CROSS AND BLUE SHIELD ASSOCIATION Technology Evaluation Center 1310 G Street, NW Washington, DC 20005 Tel: (888) TEC-4321 Fax: (202) 626-4833 www.bcbs.com</p>	<ul style="list-style-type: none"> • For a copy of their breast cancer-related technology assessments.
<p>CANCER CARE 275 Seventh Avenue, 22nd floor New York, NY 10001 Tel: (800) 813-HOPE (4673) (212) 712-8080 Fax: (212) 712-8495 www.cancercare.org</p>	<ul style="list-style-type: none"> • For their booklet called, “Helping Hand Resource Guide.” It lists groups across the country that help patients pay for their care.

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<p>CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC) 1600 Clifton Road Atlanta, GA 30333 Tel: (888) 842-6355 www.cdc.gov</p>	<ul style="list-style-type: none"> • To find out where to get a free mammogram through the National Breast and Cervical Cancer Early Detection Program (NBCCEDP). This program gives breast and cervical cancer screenings, diagnoses, and treatment to low-income women. All 50 states offer screening and diagnostic services through the NBCCEDP. And most states provide free treatment through the program, too.
<p>CENTERS FOR MEDICARE AND MEDICAID SERVICES (CMS) 7500 Security Boulevard Baltimore, MD 21244 Tel: (800) MEDICARE (633-4227) www.cms.gov</p>	<ul style="list-style-type: none"> • For information on the Medicare program, • For toll-free phone numbers for each state’s Medicaid agency. (Call 800-MEDICARE and ask for the toll-free number for your state’s Medicaid agency.) Toll-free numbers are also available online at www.hcfa.gov/medicaid/obs5.htm.
<p>COMPASSION IN DYING FEDERATION PMB 415, 6312 SW Capitol Highway Portland, OR 97201 Tel: (503) 221-9556 Fax: (503) 228-9160 www.compassionindying.org</p>	<ul style="list-style-type: none"> • To learn about issues that are important during the last stages of life.
<p>FINDCANCEREXPERTS.COM Academic Oncology Resources, LLC PMB 340 11140 Rockville Pike Rockville, Maryland 20852 (no phone service available) Fax: (301) 231-4987 www.findcancerexperts.com</p>	<ul style="list-style-type: none"> • For help getting a pathology second opinion anywhere in the country.

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<p>HEALTH LEGACY PARTNERSHIP 4770 Biscayne Boulevard, Suite 1150 Miami, FL 33137 Tel: (305) 576-4310 Fax: (305) 576-7412 www.healthlegacy.org</p>	<ul style="list-style-type: none"> • To learn more about health outcomes research, • To learn about their efforts to create a national health outcomes database.
<p>HEALTH PRIVACY PROJECT 2233 Wisconsin Avenue, NW Suite 525 Washington, DC 20007 Tel: (202) 687-0880 Fax: (202) 784-1265 www.healthprivacy.org</p>	<ul style="list-style-type: none"> • For a summary of privacy laws around the country, • To learn about privacy protections in your state.
<p>HILL-BURTON FREE CARE PROGRAM Division of Facilities Compliance and Recovery U.S. Department of Health and Human Services 5600 Fishers Lane, Room 10C-16 Rockville, MD 20857 Tel: (800) 638-0742</p>	<ul style="list-style-type: none"> • To see if you can get free or low-cost care at a Hill-Burton care center.
<p>INSTITUTE OF MEDICINE (IOM) 2101 Constitution Avenue, NW Washington, DC 20418 Tel: (202) 334-2352 Fax: (202) 334-1412 www.iom.edu</p>	<ul style="list-style-type: none"> • For two important reports on the quality of care in the United States: “To Err is Human: Building a Safer Health System” and “Crossing the Quality Chasm: A New Health System for the 21st Century.” The IOM has many good reports on health care issues.

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<p>JOINT COMMISSION ON ACCREDITATION OF HEALTHCARE ORGANIZATIONS (JCAHO) One Renaissance Boulevard Oakbrook Terrace, IL 60181 Tel: (630) 792-5000 Fax: (630) 792-5005 www.jcaho.org</p>	<ul style="list-style-type: none"> • To see if your hospital is accredited. JCAHO may also have a report on your hospital.
<p>MEDICARE (The Medicare program is administered by the Centers for Medicare and Medicaid Services.) Tel: (800) MEDICARE (633-4227) www.medicare.gov</p>	<ul style="list-style-type: none"> • For information on the Medicare program.
<p>NATIONAL CANCER INSTITUTE (NCI) Public Inquiries Office Building 31, Room 10A31 31 Center Drive, MSC 2580 Bethesda, MD 20892-2580 Tel: (800) 422-6237 www.nci.nih.gov</p>	<ul style="list-style-type: none"> • For NCI's breast cancer care guidelines. These guidelines are part of NCI's Physician Data Query (PDQ) database, • For a copy of NCI's "Consensus Statement on Adjuvant Therapy for Breast Cancer." This paper tells what NCI recommends for treating breast cancer, • For information on clinical trials.
<p>NATIONAL CENTER FOR COMPLEMENTARY AND ALTERNATIVE MEDICINE (NCCAM) NCCAM Clearinghouse P.O. Box 7923 Gaithersburg, MD 20898 Tel: (800) 644-6226 (301) 519-3153 Fax: (866) 464-3616 www.nccam.nih.gov</p>	<ul style="list-style-type: none"> • To learn about complementary and alternative care (CAM), • To find out what CAM treatments exist and what is known about them, • To find out about open CAM clinical trials.

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<p>NATIONAL COALITION FOR CANCER SURVIVORSHIP (NCCS) 1010 Wayne Avenue, Suite 770 Silver Spring, MD 20910-5600 Tel: (301) 650-9127 (877) 622-7937 Fax: (301) 565-9670 www.cansearch.org</p>	<ul style="list-style-type: none"> • For a copy of NCCS’s Cancer Survival Toolbox audiotapes. The audiotapes cover talking with doctors, making deals, solving problems, and standing up for your rights.
<p>NATIONAL COMMITTEE FOR QUALITY ASSURANCE (NCQA) 2000 L Street, NW, Suite 500 Washington, DC 20036 Tel: (202) 955-5697 Fax: (202) 955-5615 www.ncqa.org</p>	<ul style="list-style-type: none"> • To see if NCQA has rated your health plan. Ask if they have a report card or other information on your health plan.
<p>NATIONAL COMPREHENSIVE CANCER NETWORK (NCCN) 50 Huntingdon Pike, Suite 200 Rockledge, PA 19046 Tel: (888) 909-6226 Fax: (215) 728-3877 www.nccn.org</p>	<ul style="list-style-type: none"> • For a copy of NCCN’s “Breast Cancer Treatment Guidelines for Patients.”
<p>NATIONAL CONFERENCE OF STATE LEGISLATURES (NCSL) 1560 Broadway, Suite 700 Denver, CO 80202 Tel: (303) 830-2200 Fax: (303) 863-8003 www.ncsl.org</p>	<ul style="list-style-type: none"> • To find out if your state has passed breast cancer or other health care laws.

Helpful Organizations	Why We Recommend Them
<p>NATIONAL HEALTH LAW PROGRAM 2639 South La Cienega Boulevard Los Angeles, CA 90034-2675 Tel: (310) 204-6010 Fax: (310) 204-0891 www.healthlaw.org</p>	<ul style="list-style-type: none"> • For a copy of their fact sheet, “Getting the Best Out of Managed Care #2: Understanding Quality Measures.”
<p>NATIONAL LIBRARY OF MEDICINE (NLM) Building 38A, Room 8N805 Bethesda, MD 20894 Tel: (888) 346-3656 or (301) 594-5983 Fax: (301) 480-9241 www.ncbi.nlm.nih.gov</p>	<ul style="list-style-type: none"> • To find clinical trials. Visit NLM’s web site at www.clinicaltrials.gov, • To access NLM’s database, “Medline.” Medline is on the Internet at www.ncbi.nlm.nih.gov/PubMed. It is a huge database. It lists titles and abstracts of research studies published in peer-reviewed, scientific journals.
<p>NATIONAL PARTNERSHIP FOR WOMEN AND FAMILIES 1875 Connecticut Avenue, NW Suite 650 Washington, DC 20009 Tel: (202) 986-2600 Fax: (202) 286-2539 www.nationalpartnership.org</p>	<ul style="list-style-type: none"> • For the National Partnership’s Guide to the Family and Medical Leave Act (FMLA).
<p>PATIENT-CENTERED GUIDES 1005 Gravenstein Highway North Sebastopol, CA 95472 Tel: (800) 998-9938 (800) 889-8969 Fax: (707) 829-0104 www.patientcenters.com</p>	<ul style="list-style-type: none"> • To buy a copy of Musa Mayer’s book, <i>Advanced Breast Cancer: A Guide to Living with Metastatic Disease</i>. This book is also available in bookstores.

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<p>PATIENT TRAVEL c/o Mercy Medical Airlift 4620 Haygood Road, Suite 1 Virginia Beach, VA 23455 Tel: (888) 675-1405, OR National Patient Travel Helpline Tel: (800) 296-1217 www.patienttravel.org</p>	<ul style="list-style-type: none"> • For long-distance travel assistance.
<p>PHARMACEUTICAL RESEARCH AND MANUFACTURERS OF AMERICA (PhRMA) 1100 Fifteenth Street, NW Washington, DC 20005 Tel: (202) 835-3400 www.phrma.org</p>	<ul style="list-style-type: none"> • For free medicine.
<p>SOCIAL SECURITY ADMINISTRATION (SSA) Tel: (800) 772-1213</p>	<ul style="list-style-type: none"> • For information on buying into Medicare Part A or for enrolling in Medicare Part B, • To find out if you can get benefits from the Social Security Disability Insurance (SSDI) program.
<p>SUSANLOVEMD.COM P.O. Box 846 Pacific Palisades, CA 90272 (no phone service available) www.susanlovmemd.com</p>	<ul style="list-style-type: none"> • For information on how to read your biopsy report and understand your treatment choices. You can find this information on Dr. Love's web site and in her book, <i>Dr. Susan Love's Breast Book</i>, • For a good list of questions to think about when choosing a doctor. This information is on Dr. Love's web site and in her book.
<p>Y-ME NATIONAL BREAST CANCER ORGANIZATION 212 W. Van Buren, Suite 500 Chicago, IL 60607 Tel: (800) 221 2141 (English) (800) 986-9505 (Spanish) Fax: (312) 294-8597 www.y-me.org</p>	<ul style="list-style-type: none"> • For a copy of their brochure, "Understanding Your Breast Cancer Pathology Report: A Guide for Breast Cancer Patients."

10 Things to Know When Judging Medical Resources on the web

The Internet is a great place to get information fast. But you have to be careful. The National Cancer Institute recommends asking the following questions. If you don't have access to the **Internet**, you may want to contact your local public library. Public libraries often have free access to the Internet.

1. Who runs this site?

Any good health-related **web site** should make it easy to learn who controls the site.

2. What is the goal of the site?

This is related to who runs the site and who pays for the site (see #8 below). The goal of the site should be clearly stated. Look under "About This Site" or "Mission Statement." These are common titles for this kind of information. Judge carefully what you are reading. The site's goal may *not* be to give fair, correct health information. The goal may be to sell you something.

3. Where does the information come from?

Many health/medical sites post information collected from other web sites or from off-line sources. The source should be clearly labeled if the information came from somewhere else.

4. What is the information based on?

The site should give the **evidence** that its information is based on. Medical facts and figures should have references. A reference can be an article in a medical journal or a meeting of experts.

Opinions or advice should be clearly set apart from information based on research results.

5. How is the information selected?

Is there an editorial board? Do people with very good medical backgrounds review the information before it is posted?

6. How current is the information?

Web sites should be reviewed and updated regularly. Each major page should have a date. (For example: "This page last updated on 7/9/02.") It is very important that medical information be current. Even if the information has not changed, the site owners should review it often. That is the only way they can be sure the information is still valid.

7. How does the site choose links to other sites?

Web sites usually have a policy about how they choose links to other sites. But they don't always tell what that policy is. Many medical sites don't link to any other sites. Some sites link to any site that asks or pays for a link.

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8. Who pays for the site?

It costs money to run a web site. Some web sites are labors of love, but most have an outside source of funds. Again, this should be clearly shown on the site. For example, web addresses ending in “.gov” mean a government pays for them. You should know how the site pays for itself. Does it sell ads? Is it paid for by a drug company? The source of funding can affect what is there, how it is presented, and what the site owners want from the site.

9. What information about you does the site collect and why?

Web sites routinely track the paths visitors take through their sites. They want to find out what pages are being used. But many health web sites ask for you to “subscribe” or “become a member.” Sometimes this is so that they can collect a user fee (see #8) or choose information that relates to you. In all cases this will give the site personal information about you. Any site should tell you exactly what they will and will not do with your information. Many sites

sell data about their users to other companies. (For example, they could sell information about what percentage of their users are women with breast cancer.) In some cases, they may collect and reuse information that could identify you, such as your zip code, sex, and birth date. Be sure that you read and understand any “privacy policy” or words like it on the site. And don’t sign up for anything that you don’t understand.

10. How does the site interact with visitors?

There should always be a way for you to contact the site owners with problems, feedback, and questions. And someone should answer your messages in a timely way. Does the site host chat rooms or other on-line discussion areas? If so, the site should tell visitors what the terms of using this service are. Is it moderated? If so, by whom and why? It is always a good idea to spend time reading the discussion before joining in. That way you can be sure you feel comfortable being part of it.