

## Online Information, Services and Support for Metastatic Breast Cancer

Prepared by Musa Mayer, June, 2007

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<b>National Organizations</b>	<a href="#"><i>[Return to top]</i></a>
<a href="#"><u>American Cancer Society</u></a>	(800) ACS-2345
<a href="#"><u>Living Beyond Breast Cancer</u></a> <a href="#"><u>Advanced Breast Cancer webpage</u></a>	Survivors' Helpline at (888) 753-5222
<a href="#"><u>Susan G. Komen for the Cure</u></a>	(800) I'M AWARE
<a href="#"><u>The National Breast Cancer Coalition</u></a>	(800) 622-2838
<a href="#"><u>National Coalition for Cancer Survivorship</u></a>	(301) 650-9127
<a href="#"><u>The Wellness Community</u></a>	(888) 793-WELL
<a href="#"><u>Y-Me National Breast Cancer Organization</u></a>	Hotline (800) 221-2141 Spanish Hotline: (800) 986-9505
<a href="#"><u>Young Survival Coalition</u></a>	(877) YSC-1011
<a href="#"><u>Inflammatory Breast Cancer Research Foundation</u></a>	(877) 786-7422
<a href="#"><u>Sisters Network</u></a> For African American women living with breast cancer	(713) 781-0255
<a href="#"><u>The Mautner Project for Lesbians with Cancer</u></a>	(202) 332-5536
<a href="#"><u>Asian American Cancer Support Network</u></a>	(650) 967-2305
<a href="#"><u>Native American Cancer Research</u></a>	(303) 838-9359
<a href="#"><u>Nueva Vida</u></a> A support network for Latinas with cancer.	(202) 223-9100

<b>Information – General</b>	<a href="#">[Return to top]</a>
<a href="#">BreastCancer.Net</a>	Subscription e-mail service offering daily medical journal and media citations on breast cancer. Emerging research comes to your in-box.
<a href="#">National Cancer Institute - Breast Cancer webpage</a>	The National Cancer Institute breast cancer website with information on treatment, clinical trials and many other issues.
<a href="#">How Cancers Grow</a>	Easy to understand information on cancer and the process of metastases from the UK's CancerHelp.
<a href="#">NCI Fact Sheets</a>	Information from the National Cancer Institute on a variety of cancer-related topics, including coping, support, testing and treatment
<a href="#">Recurrent and Metastatic Disease</a>	BreastCancer.org website devoted to metastatic breast cancer.
<a href="#">AdvancedBC.org</a>	My dedicated web resource for advanced (metastatic) breast cancer
<a href="#">Inflammatory Breast Cancer Association</a>	

<b>Financial and legal information/assistance</b>	<a href="#">[Return to top]</a>
<a href="#">NeedyMeds</a>	Information on patient assistance programs which provide no cost prescription medications to eligible participants
<a href="#">Partnership for Prescription Assistance</a>	Mission is to “ help qualifying patients who lack prescription coverage get the medicines they need through the public or private program that's right for them.”
<a href="#">Patient Advocate Foundation Co-Pay Relief</a>	“provides co-payment assistance for pharmaceutical products to insured Americans who financially and medically qualify.”
<a href="#">U.S. Social Security Administration</a>	Metastatic breast cancer is considered a qualifying disability. (800) 772-1213
	<a href="#">Benefits for People with Disabilities</a>
	<a href="#">Benefits Eligibility Screening Tool (BEST)</a>
	<a href="#">Disability Benefits (SSA Publication No. 05-10029)</a> “Basic information on Social Security disability benefits

	<a href="#"><u>Social Security Protection If You Become Disabled</u></a> Disability Planner
	<a href="#"><u>Supplemental Security Income (SSI)</u></a> “designed to help aged, blind, and disabled people who have little or no income” “cash to meet basic needs for food, clothing, and shelter.”
<a href="#"><u>CancerAndCareers.org</u></a>	A resource for working women with cancer
<a href="#"><u>Air Charity Network</u></a>	Free air transportation (formerly AngelFlightAmerica) 877-621-7177
<a href="#"><u>Corporate Angel Network</u></a>	“Free air transportation for cancer patients traveling to treatment using the empty seats on corporate jets.” 866-328-1313

<b>In-Person Support</b>	<a href="#"><u>[Return to top]</u></a>
<i>Note: In-person support groups that serve only women with advanced breast cancer may be hard to find outside of urban areas. Groups for patients with all advanced cancers are offered in many hospitals and cancer centers, usually led by nurses or social workers. Local breast cancer support organizations may also have metastatic groups.</i>	
<a href="#"><u>The Wellness Community</u></a>	A free program of emotional support, education, and hope for people with cancer and their families. (888) 793-9355
<a href="#"><u>Commonweal</u></a>	“Cancer Help Program conducts weeklong support and learning programs for people with cancer.” (415) 868-0970
<a href="#"><u>Gilda’s Club</u></a>	Free services in a clubhouse format offering emotional and social support for cancer patients, their families and friends. 1-888-GILDA-4-U
<a href="#"><u>Cancer Care, Inc.</u></a>	Offers support services, education and information, referrals, and financial assistance.
<a href="#"><u>Sharsheret</u></a>	“Embrace” is a new program of group and individual telephone counseling designed to meet the unique needs of young Jewish women living with metastatic breast cancer. (866) 474-2774.

<b>Online Support</b>	<a href="#">[Return to top]</a>
Free from the limitations of time, money and location, women with advanced breast cancer and their families can give and receive support and share information via the mailing lists and bulletin boards listed below. Mailing lists operate via an exchange of email, while bulletin boards take the form of messages posted on websites.	
<a href="#">BCMETS</a> Mailing List and Webpage	Large, open mailing list for metastatic breast cancer patients, family members and friends. Browse and search the public archive of all messages over its eight year history. Lurkers (people who choose not to post public messages) are welcome. Very active
<a href="#">CLUB-METS-BC</a> Mailing List	Mailing list for metastatic breast cancer patients and caregivers only. Archives only searchable by list members.
<a href="#">IBC Support</a> Mailing List and Webpage	Mailing list for inflammatory breast cancer support and information.
<a href="#">Breast Cancer Action Nova Scotia (BCANS)</a> Support Forum	Bulletin board for all breast cancer, but with many advanced breast cancer patients. Very active
<a href="#">HER2 Support</a> Group Forum	Bulletin board and information for women with HER2+ breast cancer. Very active
<a href="#">Her2/Recurrence Board for Survivors</a>	Support for women with HER2+ breast cancer
<a href="#">"Recurrence and Metastatic Disease"</a> Discussion Board	"Braving more treatment and managing the ups and downs with others who care." Very active discussion board at <a href="#">BreastCancer.org</a> .
<a href="#">Young Survival Coalition</a> Bulletin Board	Support for young women with metastatic disease
<a href="#">"Our Corner"</a> Message Board	A forum for women living with metastatic disease at <a href="#">Living Beyond Breast Cancer</a>
<a href="#">CaringBridge</a>	"CaringBridge offers free, easy-to-create web sites that help connect friends and family when they need it most."
<a href="#">Making Memories</a>	This organization provides an opportunity for advanced breast cancer patients to fulfill a dream or wish.

<b>Resources for Caregivers</b>	<a href="#">[Return to top]</a>
<a href="#">Association of Oncology Social Work</a>	Tips for managing cancer and caregiving
<a href="#">Caregiver Resource Directory</a>	Offers resources, facts, and advice about caring for a loved one, as well as the caregiver.
<a href="#">National Alliance for Caregiving</a>	Dedicated to providing support to family caregivers and health professionals, and increasing public awareness of issues facing family caregivers.
<a href="#">The National Family Caregivers Association</a>	"Speaks up for the more than 50 million Americans who care for loved ones with a chronic illness or disability or the frailties of old age."

<b>Information Seeking</b>	<a href="#">[Return to top]</a>
<a href="#">National Comprehensive Cancer Network (NCCN) Guidelines</a>	The National Comprehensive Cancer Network has released new guidelines for the treatment of breast cancer, in decision-tree format.
<a href="#">CancerGuide: How to Research the Medical Literature</a>	Steve Dunn's online, step-by-step, thorough introduction to researching cancer and its treatments.
<a href="#">PubMed</a>	Search the Medline database of medical/scientific citations and abstracts. Includes overview and tutorial on search methods, plus links to some full text articles.
<a href="#">PDQ Health Professional Statement on Breast Cancer</a>	PDQ is a cancer database maintained by the National Cancer Institute (NCI) and contains statements, updated monthly, of the most recent treatments, standard and investigational treatment protocols, clinical trials, and major cancer treatment centers and physicians. Peer-reviewed summary on breast cancer treatment for health professionals, reviewed monthly. Available in Spanish, and in a version for patients.
<a href="#">Levels of Evidence for Adult Cancer Treatment Studies (PDQ)</a>	An easy-to-follow description of how scientific evidence is evaluated for the PDQ documents and for cancer research in general.
<a href="#">Medscape</a>	Continuing medical education, conference and research reports for physicians and consumers.

<b>Treatment Information</b>	<a href="#">[Return to top]</a>
<a href="#">How To Find a Doctor or Treatment Facility If You Have Cancer</a>	From the NCI Cancer Facts, what you need to know about finding quality medical care
<a href="#">NCI-Designated Cancer Centers</a>	"60 research-oriented institutions across America that National Cancer Institute recognizes for scientific excellence and for their extensive resources focused on cancer and cancer-related problems." Top breast cancer oncologists involved with clinical research are usually affiliated with one of these. If you are being treated elsewhere, a consultation or second opinion with one of these doctors can be helpful at critical points in your treatment, alerting you to clinical trials or emerging treatments.
<a href="#">MedlinePlus</a>	A service of the National Library of Medicine and the National Institutes of Health, consumer-friendly information on drugs, medical encyclopedia and dictionary
<a href="#">RxList.org</a>	FDA-approved labeling information on prescription drugs in an easy-to-read format.

<a href="#">Drugs@FDA</a>	An FDA web site to help consumers and health professionals find information about approved drug products. Gives the history of a drug's approval.
<a href="#">Mayo Clinic Drugs and Supplements Index</a>	Drug information in consumer-friendly language.
<a href="#">ChemoCare.com</a>	Information about drugs used in cancer treatment, in patient-friendly format.
<a href="#">Harvard Medical School Family Health Guide to Diagnostic Tests</a>	
<a href="#">LabTestsOnline.org</a>	Helps patients and caregivers to better understand the many clinical lab tests that are part of routine care as well as diagnosis and treatment of a broad range of conditions and diseases.
<a href="#">NCI Dictionary of Cancer Terms</a>	A good cancer dictionary and glossary.

<b>Clinical Trials</b>	<a href="#">[Return to top]</a>
<a href="#">Learning about Clinical Trials</a>	The National Cancer Institute's (NCI) introduction to clinical trials.
<a href="#">Glossary of Clinical Trials Terms</a>	From ClinicalTrials.gov.
<a href="#">NCI Clinical Trials Search Page</a>	
<a href="#">ClinicalTrials.gov</a>	User-friendly search site developed by the National Library of Medicine and the National Institutes of Health. Companies developing drugs are required to list Phase II and III trials for their drugs here. See "Understanding Clinical Trials."
<b>Cancer Cooperative Research Groups</b>	<p>The Cooperative Groups design and conduct many of the studies done in advanced breast cancer after drugs are approved.</p> <ul style="list-style-type: none"> <li>▪ <a href="#">Cancer and Leukemia Group B (CALGB)</a></li> <li>▪ <a href="#">Eastern Cooperative Oncology Group (ECOG)</a></li> <li>▪ <a href="#">National Cancer Institute of Canada Clinical Trials Group (NCIC CTG)</a></li> <li>▪ <a href="#">The National Surgical Adjuvant Breast and Bowel Project (NSABP)</a></li> <li>▪ <a href="#">North Central Cancer Treatment Group (NCCTG)</a></li> <li>▪ <a href="#">Southwest Oncology Group (SWOG)</a></li> </ul>
<a href="#">The Pharmaceutical Research and Manufacturers of America (PhRMA)</a>	Professional association of drug manufacturers and biotech companies. <a href="#">2006 Report: New Medicines in Development in Cancer</a>

<b>Complementary and Alternative Therapy</b>	<a href="#">[Return to top]</a>
<a href="#">National Center for Complementary and Alternative Medicine</a>	Information from the CAM section of the National Institutes of Health.
<a href="#">Thinking about Complementary and Alternative Medicine (CAM)</a>	National Cancer Institute Brochure for patients.
<a href="#">MSKCC: Information Resource: About Herbs, Botanicals &amp; Other Products</a>	Memorial Sloan-Kettering Cancer Center integrative medicine resource.
<a href="#">The Annie Appleseed Project</a>	Provides information, education, advocacy and awareness for people with cancer, family and friends interested in, complementary, alternative medicine (CAM), natural therapies from the patient perspective.
<a href="#">Choices In Healing: Integrating The Best of Conventional and Complementary Approaches to Cancer</a>	Michael Lerner's thoughtful book on CAM, online in its entirety
<a href="#">ACS: Complementary and Alternative Therapies</a>	American Cancer Society's website on CAM.

<b>Supportive Care</b>	<a href="#">[Return to top]</a>
<a href="#">Coping with Cancer</a>	National Cancer Institute, with links for NCI materials coping with fatigue, pain and other side effects/treatment complications, as well as emotional and nutritional concerns and end of life issues.
<a href="#">Cancer Supportive Care</a>	A broad series of articles on supportive care for cancer patients and health professionals.
<a href="#">Chemotherapy and You: A Guide To Self-Help During Treatment.</a>	Basic principles for handling side effects of treatment.
<a href="#">The Xtra Support Program</a>	From Roche, a free program involving follow-up from an oncology nurse, for added support with Xeloda therapy..
<a href="#">Pain PDQ</a>	National Cancer Insitute PDQ guides for pain management for health professionals and patients (also in Spanish)
<a href="#">Cancer-pain.org</a>	"Connect to the latest and most accurate information on state-of-the-art management of cancer pain for patients, caregivers and healthcare professionals."

<a href="#"><u><b>Pain Control: A Guide for People with Cancer and Their Families</b></u></a>	National Cancer Institute guide for pain control.
<a href="#"><u><b>Radiation Therapy and You: A Guide To Self-Help During Treatment.</b></u></a>	A basic introduction to the topic of radiation treatment, how and why it is done, and coping with the side effects.
<a href="#"><u><b>American Cancer Society Tender Loving Care Catalog</b></u></a>	Hats, scarves, mastectomy products and more...

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<b><i>Patient Active Guide to Living with Advanced Breast Cancer</i></b> <a href="#"><u><i>download PDF or read online</i></u></a>	A helpful new resource from the Wellness Community and Living Beyond Breast Cancer
<b><i>When Cancer Returns: Meeting The Challenge Again</i></b>	NCI publication, touches on many of the major issues metastatic breast cancer patients will face.
<b><i>I Still Buy Green Bananas: Living with Advanced Breast Cancer</i></b>	Helpful brochure published by Y-Me
<b><i>The Median Isn't the Message</i></b>	How to make sense of statistics by evolutionary biologist Stephen Jay Gould. "The wisest, most humane thing ever written about cancer and statistics." –Steve Dunn, editor, CancerGuide.org
<b><i>The Shock of Recurrence</i></b>	From Musa Mayer's <i>Advanced Breast Cancer: A Guide to Living with Metastatic Disease</i> . <i>Look for other excerpts on this website.</i>
<b><i>Within Measured Boundaries</i></b>	Jenilu Schoolman's essay on living with advanced breast cancer.
<b><i>Conversations From The Heart</i></b>	Resources for Talking With Children About a Parent's Serious Illness, by Janet Perloff and Victoria Rizzo
<b><i>The Quiet War</i></b>	Film profiles of five women living with metastatic breast cancer, plus expert interviews on treatment, coping. DVD from AffinityFilms. (888) 353-4325

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