

NAVIGATING YOUR BREAST CANCER DIAGNOSIS

Information &
Resources



Who We Are

Our purpose is to provide support through sharing common experiences focused on people's personal struggles. We offer our knowledge, encouragement, and friendship to let each person know that they are not alone while they face breast cancer.

Bosom Buddies of Arizona has been providing information, monthly meetings, care, and comfort since 1982, when five women decided they wanted to share their experiences and journeys through breast cancer with other individuals. These women knew that part of the healing process was giving support and sharing information to help ease the next woman's journey. So we began: Women reaching out to other "buddies" in need.

We support women and men of all ages and in all stages of breast cancer. We support their caregivers as well.

If you have found a breast lump, have been diagnosed with breast cancer, or if you have a friend or loved one who might benefit from our services, we are here for you. If you need information, support, or just someone to talk to, please contact us on our website at www.BosomBuddies-AZ.org or call us at 602-265-2776.

Bosom Buddies® Inc.
is a 501(c)(3) non-profit organization.

P: 602-265-2776
Hotline: 602-231-6648
Info@BosomBuddies-az.org

www.BosomBuddiesaz.org

BOSOM BUDDIES OF ARIZONA

Navigating your breast cancer journey information and resources

You have just been diagnosed with breast cancer and are totally overwhelmed. There are so many people offering advice and so much literature to read online or in books. Where do you turn?

At Bosom Buddies of Arizona (BB), our goal is to simplify your life if you live in Maricopa County, Arizona, although we think this resource can help people throughout the country.

The amount of information is overwhelming, and we have not tried to be all things to all people. Our intent is to provide area-specific information on certain topics. In this guide we have chosen specific topics where we can help with resources right within our community.

Let's start by assuming you have been diagnosed with breast cancer, and hopefully, you have investigated getting a second opinion. Through your insurance plan you have been directed to a



Let's start by assuming you have been diagnosed with breast cancer, and hopefully, you have investigated getting a second opinion. Through your insurance plan you have been directed to a specific set of doctors and/or specialists who have taken you through surgical and treatment options.

However, you may have additional questions and concerns that we can help address, including seeking insurance, battling legal issues, finding a comprehensive cancer center, locating a screening or testing facility, or pursuing a prosthesis or reconstruction. We can also help if you have lymphedema, want to add complementary and/or alternative medicines, find a support group, or join a clinical trial. Maybe you want to advocate for breast cancer issues, understand what it means to be a survivor, or use your talents to help others. You will find answers here.

In each section of this informational booklet, we have provided a definition of the topic, a list of questions, and a list of resources.

REMEMBER: Knowledge is Power! The more you know, the more intelligent questions you can ask so that you can really take control and become an integral part of your own care, healing, and survival.

We hope that you find "Navigating Your Breast Cancer Diagnosis: Information and Resources" helpful. We have made every effort to ensure that the information contained in this guide is accurate. Before you visit any vendors contained in this resource guide, please contact them to verify that they have not moved.

This booklet provides general information on breast cancer and resources and is not intended to be a substitute for professional medical advice, diagnosis, or treatments.

Be of good health.

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INTRODUCTION

1

TAKE SOME TIME

Most women don't need to rush into treatment. By taking some time to learn about breast cancer, you can make better choices. Ask your doctor if your treatment decisions can wait a few weeks.

LEARN ABOUT YOUR BREAST CANCER

11

Your treatment depends on your diagnosis. Ask your doctor or nurse the following questions: What is my diagnosis? Are there any other names for it? What are my treatment options? Try to get a second opinion on both your diagnosis and treatment options.

ASK QUESTIONS

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Ask lots of questions. If you can, bring a friend or family member to your appointments. Before choosing a treatment, ask your doctor or nurse: What is this treatment supposed to do? What is my risk of getting breast cancer again if I complete this treatment? What if I don't complete treatment?

How likely am I to be alive in 5 or 10 years if I do have this treatment? What are the negative side effects? Will any side effect last for the rest of my life? Also, find out how many new breast cancer patients your doctor treats each year. Studies show that the best patient outcomes result from doctors who treat at least 30-50 new patients per year.

1v INVESTIGATE MEDICAL EVIDENCE

There is no “one size fits all” solution for breast cancer. Ask your doctor or nurse for evidence-based guidelines explaining which treatments are most likely to work. Get information that you can trust.

GET SUPPORT

You can get help in dealing with your emotions, transportation, and finances or solving problems with family, treatments, and insurance. Contact Bosom Buddies @ 602-265-2776 or consider attending one of our monthly support group meetings (details at www.BosomBuddies-AZ.org).

Adapted from "The Guide to Quality Breast Cancer Care."
National Breast Cancer Coalition Fund

www.qualitycareguide.stopbreastcancer.org



CHAPTER 1

GENERAL BREAST CANCER INFORMATION

If you have just been diagnosed, we recommend the following websites where you can obtain some basic information about breast cancer:

ARIZONA BREAST CANCER RESOURCE GUIDE



www.azbreastcancer.org

An online guide that offers general breast cancer information, financial resources, and other useful information.



breastcancer.org

A non-profit organization dedicated to providing information and community support to those touched by breast cancer. Provides free booklets and up-to-date medical information and research, as well as a friendly and compassionate atmosphere. You can sign up for e-mail updates about current research, online events and more.



www.cancer.net/breast 1-888-651-3038

Oncologist-approved cancer information from the American Society of Clinical Oncology. This site provides information for those who were recently diagnosed or are undergoing treatment for breast cancer.



www.cancer.org

Website of the American Cancer Society. Provides free booklets, up-to-date medical information and research, and a supportive warm community in a friendly and compassionate atmosphere.



NATIONAL CANCER INSTITUTE

(within the National Institute of Health) 1-800-4-CANCER



This is the world's largest organization solely dedicated to cancer. Comprehensive information, searchable data, multiple related links, and access to booklets both online and mailed to you free of charge.

www.patientresource.com



Contains a wealth of information on many different types of cancers. Publishes a variety of free publications on all aspects of cancer, including a financial resource guide and women's cancer guide.

ww5.Komen.org



Website of Susan G. Komen, known for its variety of information on breast cancer and online support.

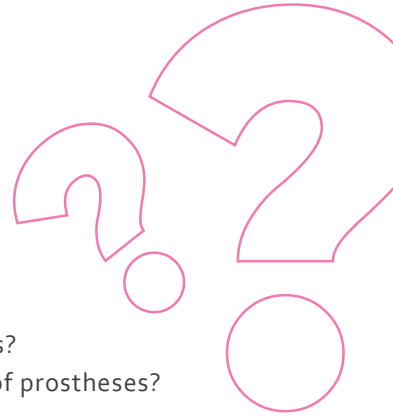
CHAPTER 2

HEALTHCARE, FINANCIAL, INSURANCE, LEGAL, PRESCRIPTIONS, RESOURCES

Insurance companies in Maricopa County and throughout the United States are offering new and varied in health care coverage. Traditional insurance allows patients to select any doctor for primary or specialty care. Managed care limits one's choice of doctors or hospitals, but these plans may offer more preventive care services and lower costs. If you have the opportunity to choose an insurance plan, do so very carefully and wisely. Your monthly insurance payment may be the most important investment you make. Read your policy very carefully and know what your coverage is. Many experts advise that you read the exclusions first. Many insurance companies require preauthorization for many medical tests, surgeries, procedures, and prescriptions.



ASK QUESTIONS



- Are annual examinations and screening mammograms covered?
- What is the policy on new therapies or participation in clinical trials?
- What is the policy for covering the cost of prostheses?
- Do you cover reconstruction surgeries?
- Who can I talk to if my care needs to be improved?
- Will the plan pay a percentage of the cost if I seek care from doctors outside of my network?
- Does the policy cover a second opinion?
- What can I expect my copay or financial liability to be?
- Can I self-refer to specialists, or must my primary care physician make referrals to specialists?
- What is the amount of my deductible and what services are applied towards my deductible?
- Are my physicians and healthcare facilities in or out of network?

RESOURCES

Please note that multiple resources have several offerings outside of placement in the below list. Category is based on specialty.

HEALTHCARE AND INSURANCE

Arizona Health Care Cost Containment System (AHCCCS) – Maricopa County

www.azahcccs.gov / 602-506-3000

Medical insurance program for low income county residents (Arizona's Medicaid Program).

General Information;
Member and Provider Services;

Enrollment:

602-417-4000

Eligibility: (in state outside of Maricopa County)

1-800-654-8713

Eligibility: (out of state)

1-800-523-0231



Arizona Life Lines Insurance Services Outside Maricopa County

www.arizonalifelines.com / 623-435-5511 / 1-888-543-5637

Assists individuals, families and small groups with determining their needs for the right health plan. Specializes in high risk and hard to place health and life. Offers assistance in understanding COBRA and HIPPA.



Valleywise Health

www.valleywisehealth.org / 602-344-5011

A resource for Maricopa County residents. You must have applied for and been denied AHCCS coverage to participate in the Financial Assistance Program, which uses a sliding scale to determine what you pay based on your income level. MIHS can help, even if you are uninsured or underinsured.

Medicare

www.medicare.gov / 1-800-MEDICARE

The U.S. government's health insurance program for those who are 65 or older, some disabled people under age 65, and people with End-Stage Renal Disease (permanent kidney failure treated with dialysis or a transplant). Administered by The Centers of Medicare and Medicaid Services within the U.S. Department of Health and Human Services.



Mission of Mercy-Arizona

www.amissionofmercy.org/602-861-2233

Provides free healthcare, dental care, and prescription medications to the uninsured or underinsured.



Well Woman Healthcheck Program

www.wellwomanhealthcheck.org /1-888 257-8502 or 602-344-2602

Operated by the Arizona Department of Health Services through a cooperative agreement with the Centers for Disease Control and Prevention. Provides free screening (clinical breast exam, mammogram, pelvic test, Pap test) to women who qualify. Some treatment programs are also available.

Breast & Cervical Cancer Program

<https://azdhs.gov/documents/prevention/tobacco-chronic-disease/cancer-prevention-control/bcctp/bcctp-provider-application-packet.pdf>

Assists to insure individuals that qualify for WWHP, but were not diagnosed through it. Through the BCCTP, AHCCCS coverage is provided to all women who are found to have breast or cervical cancer, regardless of where they were screened.

COPAY AND PRESCRIPTION COVERAGE

Many pharmaceutical companies provide financial assistance with prescription medications.

Arizona Copper X Card

www.azgovernor.gov / 1-888-227-8315

Available to any AZ resident, this free prescription discount card saves an average of 20% off the price of prescription medications.



Cancer Care

www.cancercopay.org / 1-800-813-4673

Offers co-pay assistance, as well as free professional support through counseling, support groups, education workshops, publications, financial assistance, and community programs.


Cancer Supportive Survivorship Care www.cancersupportivecare.com

Drug Assistance Program from pharmaceutical companies

Co-Pay Relief

www.copays.org / 1-866-512-3861

Provides assistance with co-pays.



Smiley Wiley Breast Cancer Foundation

www.smileywiley.org / 1-561-632-8631


Provides financial assistance to men and women with breast cancer who can't meet their health insurance deductibles.

LODGING

Editha House

www.edithahouse.org / 602-388-4920

Provides affordable lodging for adult cancer patients and their adult caregivers traveling to Phoenix, Arizona for medical treatment.



Hope Lodge www.cancer.org/Treatment/SupportProgramsServices/HopeLodge/Index

Free temporary housing program through the American Cancer Society.

Sisters Network Inc

www.sistersnetworkinc.org

Provides assistance with medical-related lodging, co-pays, office visits, prostheses and mammograms.

TRAVEL

Air Care Alliance	www.aircareall.org
Air Charity Network	1-877-621-7177 www.aircharitynetwork.org
Angel Wheels	1-800-768-0238 www.angelwheels.org
Angel Flight West	1-888-426-2643 www.angelflightwest.org
Cancer Care	1-800-813-4673 www.cancercares.org
Corporate Angel Network	1-866-328-1313 www.corporateangelnetwork.org
Glendale Transit	480-222-4106 www.glendaleaz.com
Mercy Medical Airlift	1-800-296-1217 www.mercymedical.org
Quality Transportation Service	602-371-1000 Assisted transportation services for the elderly, disabled, and those confined to wheelchairs for a fee.
21st Century C.A.R.E	1-888-850-1622 www.21stcenturycare.org

MISCELLANEOUS

About Care Support Services for the Homebound www.aboutcare.org / 480-802-2331

Provides transportation, shopping, errands, respite care, computer assistance, and minor home repairs for residents of Gilbert and Chandler.

Cleaning for a Reason

<http://cleaningforareason.org>

Provides free housecleaning services for women undergoing chemotherapy.

Dignity Health at St. Joseph's Medical Center

Financial Counselor: 1-888-670-6341

Encourage clients to apply for AHCCS. If approved, only pay for initial consultation.

AHCCS DES Office: apply online- azahccs.gov.

If client is denied AHCCS, place a request for St. Joseph's charity program- must have proof of AHCCS denial.

Food Stamps application and questions

Healtharizona.com / 602-542-9935

GoFundMe.com - Online fundraising opportunity for individual patients.


Hope For Young Adults with Cancer

Hope4yawc.org

Mission is to making life easier for young adults, ages 18-40, living with cancer. It provides direct financial support to young people faced with cancer.

Meals on Wheels

www.mealcall.org/meals-on-wheels/az
602-264-2255



Synergy Home Care

www.synergyhomecare.com / 480-947-1234
Provides such services as personal care, meal preparation, laundry, light housekeeping, transportation, grocery shopping, errand services, etc.

The Tiffany Foundation

<http://www.thetiffanyfoundation.org/home>
From their website: This organization empowers people living with cancer with "Hope. Help. Now," through grants to help pay rent, medical copays, transportation cost, child care, and other related expenses

Triple Step Toward the Cure

www.triplesteptowardthecure.org
Provides general and financial support for women diagnosed with triple negative breast cancer and their families. Includes meals delivered, rent, utilities, transportation related to treatment, housekeeping. Application is necessary.


U.S National Library of Medicine

www.nlm.nih.gov
Contains information on financial assistance, health insurance, and Medicare



Well Women Health Center

602-323-3418 This reference is for women who have not yet been diagnosed with breast cancer. Can possibly help with screening and diagnosis costs. Application is necessary.



Native American Cancer Research

www.natamcancer.org / 1-800-537-8295

A non-profit organization dedicated to helping improve the lives of Native American patients and survivors through education, spirituality, communication, treatment, clinical trials, and health information.

The Singletons.

www.thesingletonsaz.org / 480-818-5285

Support for single moms with cancer.

Patient Advocacy Foundation

www.patientadvocate.org / 1-800-532-5274

Provides medication and arbitration services to patients that help remove obstacles to healthcare including medical debt crisis, insurance access issues, and employment issues for patients with chronic debilitating and life threatening illnesses. Provides assistance and information on financial issues such as co-pays, too.

Tammy D Foundation

www.tammydfoundation.org

Provides assistance with transportation, cooking, light housekeeping, personal care, child care, and more.

The Joy Bus

www.thejoybusdiner.com

The Joy Bus is a not-for-profit organization with the sole purpose of relieving the daily struggles of homebound cancer patients with a fresh, chef-inspired meal.

LEGAL RESOURCES

AZ Law Help

602-258-3434
www.azlawhelp.org

Maricopa County Bar Association

602-257- 4200
www.Maricopabar.org

State Bar of Arizona

602-252-4804
www.azbar.org

Offers numerous public information brochures, free of charge.

Compassion and Choices

1-800-247-7421
www.compassionandchoices.org

Created in 2005 by the unification of Compassion in Dying and End-of-Life Choices, this organization supports, educates and advocates for choice and care at the end of life. They work for improved care and expanded options at the end of life, with effective care for every dying person. They support comprehensive pain control and palliative care, as well as legal aid in dying, if suffering is unbearable. They have 95 local groups across the country.

National Conferences of State Legislatures (NCSL)

1-202-624-5400
www.ncsl.org

A way to find out if your state has passed breast cancer or other health care laws.

TEN STEPS TO PROTECTING THE LEGAL RIGHTS OF BREAST CANCER PATIENTS

- 1 Read your health insurance policy carefully.
- 11 Determine if the treatment prescribed by your physician is covered or excluded by your policy.
- 111 Find out about the appeals process under your insurance policy.
- 1v Consult with an expert who is knowledgeable about health insurance law.
- v Personalize your written case with your insurance company.
- v1 Obtain copies of your medical records.
- v11 Document everything!
- v111 Ask your physician to advocate for your treatment.
- 1x Be prepared to fight!
- x Familiarize yourself with the Patient Protection and Affordable Care Act.

CHAPTER 3

BREAST CANCER CENTERS

A breast cancer center coordinates a specialized team of health professionals to address breast cancer concerns, facilitating diagnoses, treatments, education, and emotional support at one central location.

At the very least, the team should include a surgeon, pathologist, radiologist, oncologist, plastic surgeon, and various support team members.



QUESTIONS TO ASK



- What medical services does the center offer?
- What specialists are on staff?
- Do you have a second opinion program?
- What hospitals are associated with the center?
- How many breast surgeries are performed here each year?
- What types of surgeries are completed (e.g. lumpectomy, mastectomy, etc.)?
- What education and support programs do you offer?
- Do you have a resource library?
- Is my insurance accepted here?
- Will you bill my insurance company?
- If I do not have insurance, who can help pay for these services?



RESOURCES

CANCER CENTER REFERRALS

American College of Surgeons approved cancer programs

www.facs.org/cancer / 1-800-621-4111

National Cancer Institute's designated

Comprehensive cancer centers

www.cancer.gov / 1-800-4-CANCER

HOSPITALS /FACILITES WITH BREAST CANCER CENTERS

Banner Baywood Medical Center

www.bannerhealth.com / 480-321-4444

Center for Women's Health

6444 E. Baywood Ave., Mesa, AZ 85206

Banner Boswell Medical Center

www.bannerhealth.com / 623-832-4000

10401 West Thunderbird Blvd., Sun City, AZ 85351

Banner Del Webb Medical Center

Louisa Kellam Center for Women's Health

www.bannerhealth.com / 623-524-4000

14502 West Meeker Blvd., Sun City West, AZ 85375

Banner Desert Medical Center

480-412-3000

Multi-Disciplinary Breast Cancer Clinic

Banner MD Anderson Cancer Center

www.bannerhealth.com / 480-256-6444
2946 E. Banner Gateway Dr., Gilbert, AZ 85234

**Banner Good Samaritan Medical Center
Laura Dreier Breast Center**

www.bannerhealth.com / 602-640-3131
(to schedule a screening mammogram).

For all other questions call 602-839-6300
1111 East McDowell Rd., Phoenix, AZ 85006

**Banner Thunderbird Medical Center
Breast Cancer Clinic**

www.bannerhealth.com / 602-865-5555
5555 W. Thunderbird Rd., Glendale, AZ 85306

**Cancer Treatment Center of America at
Western Regional Medical Center**

www.cancercenter.com/western-hospital.cfm
623-207-3000
14200 W. Filmore, Goodyear, AZ 85338

**Chandler Regional Medical Center
Women's Imaging Center**

480-728-3900 Option #1 / www.chandlerregional.org
1727 W. Frye, Suite #110, Chandler, AZ 85224

Maricopa Integrated Health System

602-344-1970 / www.mihs.org

Phoenix Cancer Center
2525 East Roosevelt St., Phoenix, AZ 85008

Mayo Clinic 480-301-8000
www.mayoclinic.org/arizona
13400 East Shea Blvd., Scottsdale, AZ 85259

Mayo Clinic

480-301-8000 / www.mayoclinic.org/arizona
13400 East Shea Blvd., Scottsdale, AZ 85259



Mayo Clinic Hospital

480-515-6296 / www.mayoclinic.org/mchospital-sct
5777 East Mayo Blvd., Phoenix, AZ 85054

Native Health

602-279-5262 / www.nativehealthphoenix.org
Started in 1978, this private, non-profit organization provides a wide range of programs in primary medical care, health promotion and prevention, wellness programs, and behavioral health programs.



St. Joseph's Hospital and

Medical Comprehensive Cancer Center

602-406-6621 / www.stjosephs-phx.org
350 West Thomas Rd., Phoenix, AZ 85013



Scottsdale Healthcare Osborn

480-882-4000 or 877-898-6569 / www.shc.org
7400 East Osborn Rd., Scottsdale, AZ 85251



Joint Commission on Accreditation of Healthcare Organizations (JCAHO)

630-792-5000 / www.jcaho.org

Check to see if your hospital is accredited.
JCAHO may also have a report on your hospital.



CHAPTER 4

BREAST CANCER AND GENETICS

Family history of breast cancer increases a woman's chance of developing breast cancer in her lifetime. However, over 75% of breast cancer occurs in women who have no family history of breast cancer at all. Only about 5-10% of breast cancers are caused by genetic changes (mutations) that are passed down in her family (inherited).

When a woman is diagnosed with breast cancer, she will often receive genetic counseling. A genetic counselor takes a detailed family history and helps map out the risk of certain cancers within a family. Genetic testing for inherited cancer syndromes may be appropriate for some women.

The most important genetic mutations that increase the risk of breast cancer are BRCA 1 and BRCA 2. These mutations increase a woman's risk of developing breast cancer by the time she is 70 years old to over 85%. BRCA 1 and BRCA 2 also significantly increase risk of ovarian cancer and pancreatic cancer. Men who carry the BRCA 1 or BRCA 2 mutations also have higher risk of breast cancer, prostate cancer, and melanoma. It is critically important that the members of one's family, including siblings, parents, and children, be aware if a BRCA mutation is discovered. These other family members could be tested also and take important steps to prevent cancer or detect it earlier once their carrier status is known.



Even if a person tests negative for BRCA 1 or BRCA 2, genetic counseling and test results are still important in breast cancer care. In recent years, several other mutations have been discovered which increase breast cancer risk, though not to the level of the BRCA mutations. If a person's lifetime risk of breast cancer is greater than 20%, then annual 3D mammograms are inadequate for screening. Current recommendations for higher-risk women include annual 3D mammogram, and annual screening breast MRI at the 6-month interval. For example, a mammogram in January, and then an MRI in June.

There are also now direct to consumer "home test" kits available for BRCA testing, from some of the same companies that test for family ancestry and ethnic background. These kits, however, only test for three BRCA mutations, when there are about 1,000 known BRCA mutations. These home test kits also do not check for other genetic mutations, some of which may increase lifetime breast cancer risk to as much as 40%. A negative home BRCA test may give people a false sense of security as to their true cancer risk. It is important that people who are concerned about breast cancer risk discuss their concerns with their health care provider, who can help them understand their cancer risk even beyond breast cancer and assist them to access quality genetic counseling and testing.

Some people worry about genetic testing and counseling because they fear that the results could be used by insurers or employers to discriminate against them. The Genetic Information Nondiscrimination Act of 2008 (GINA), states that it is unlawful for any insurance company to request, require, or use one's

Some people worry about genetic testing and counseling because they fear that the results could be used by insurers or employers to discriminate against them. The Genetic Information Nondiscrimination Act of 2008 (GINA), states that it is unlawful for any insurance company to request, require, or use one's genetic information to determine one's eligibility for health insurance or their premiums, contribution amounts, or the terms of their coverage. This law also applies to employment discrimination. Further, the results of genetic testing are considered "Protected Health Information" (PHI), and the release of this information is strictly limited by the Health Insurance Portability and Accountability Act of 1996 (HIPAA), which protects patient privacy.

RESOURCES

For further information, and resources regarding genetic testing and counseling, please check the following links:

- <https://www.cancer.org/cancer/breast-cancer/risk-and-prevention/genetic-testing.html>
- <https://myriad.com/patients-families/disease-info/breast-cancer/>
- <https://arizonaoncology.com/treatments-services/medical-specialties/genetics/>
- <https://www.honorhealth.com/medical-services/cancer-care/early-detection/genetic-testing-counseling>
- <https://www.cancercenter.com/diagnosing-cancer/genetic-and-genomic-testing>

CHAPTER 5

SCREENING TESTING RESOURCES FACILITIES

Whether you are having a mammogram or have been diagnosed with breast cancer and require further testing, it's very important that you choose the right facility. If you have health insurance, your physician will recommend a screening facility. If you do not have health insurance, there are resources listed below. Either way, there are important questions that you must ask about the facility where you will undergo testing.

QUESTIONS TO ASK

- Is the facility certified by the Mammography Quality Standard Act (MQSA)?
- What does the test cost?
- Will you bill my insurance?
- What insurance programs do you accept?
- Are there any low-cost mammography programs which I might qualify for?
- What preparation is required for my test(s)?
- Should my mammogram be scheduled at a certain time of the month?



RESOURCES

American Breast Cancer Foundation


410-730-5105 / www.abcf.org



American Cancer Society

602-224-0524 or 1-800-227-2345 / www.cancer.org

Maintains a county-wide referral list of low-cost mammography programs



Arizona Institute for Breast Health

480-860-4200 / www.aibh.org

9055 E. Del Camino Drive, Suite #200, Scottsdale, AZ 85258

Offers a second opinion, completely free of charge, to women who have been diagnosed with breast cancer. The volunteer team of physicians and medical professionals are breast health experts whose specialties include breast radiology, breast surgery, medical oncology, radiation oncology, reconstructive surgery, and breast pathology. This team evaluates the best medical and surgical options for the preservation of a woman's body and emotional wellbeing, as well as the continued quality of her life.

Center for Women's Health Woman's Wellness Clinic

602-406-3715

500 West Thomas Rd., Suite #800, Phoenix, AZ 85013

Part of St. Joseph's Hospital and Medical Center, this program offers physical exams and health education for women who have no insurance or whose insurance does not cover well-woman exams. Call for information and an appointment.



Medicare and Medicaid
Covers screening and testing
(see section on Insurance for referral numbers).



Well Woman Healthcheck Program

1-800-232-4636 or 602-542-1219 or 1-888-257-8502 to find nearest provider

www.azdhs.gov/hsd/healthcheck/wellwomen (Arizona)

www.cdc.gov/cancer/nbccedp (National)

This program is operated by the Arizona Department of Health Services through a cooperative agreement with the Centers for Disease Control and Prevention. It provides free screening (clinical breast exam, mammogram, pelvic test, Pap test, etc.) to women that qualify, alongside a few treatment programs.



**ALL SCREENING AND TESTING
REQUIRE A REFERRAL AND A
WRITTEN PRESCRIPTION FROM A
PHYSICIAN.**



CHAPTER 6

PROSTHESES BRAS-HATS-WIGS

A breast prosthesis is an artificial breast-shaped form that can be worn under clothing after a mastectomy. After your physician has said that you are ready to purchase a breast form and has given you a prescription, it's time to review some questions to find a breast form that will work for you. Make sure that you make an appointment with a fitter who is trained to fit women after breast surgery. Also, check with your insurance company or Medicare to see if it covers prosthesis and/or specialty clothing. Obtain specifics on what is covered and what is not.

- 1 Comfort and fit should be uppermost in your mind. A prosthesis cannot be returned, so take your time when shopping.
- 11 Make an appointment with a fitter who is trained to fit women who have had breast surgery.
- 111 Write "surgical" on your bill to increase likelihood of insurance coverage.
- 1v Wigs are often referred to as hair prosthetics so that insurance companies and Medicare will cover their costs.

QUESTIONS TO ASK



- What products will my insurance company cover?
- What specific products do you carry?
- Do you provide in-home private consultations and is there a fee?
- Am I required to pay up-front, or will you bill my insurance company?
- Do you provide any discounts?

RESOURCES

Arizona Wig Boutique

480-429-3778 / 7074 E. 5th Ave., Scottsdale, AZ 85251

Barbara's Mastectomy Boutique

602-234-9568
5350 N. 16th St., #101, Phoenix, AZ 85016

Home visits by appointment.

Boutique of Hope

480-256-3220

Banner MD. Anderson Cancer Center

2946 E. Banner Gateway Dr., Gilbert, AZ 85324

Classy Sisters Wigs

602-993-8090 / www.classysisterswigs.com
15620 N. 35th Ave., #4, Phoenix, AZ 85053

Fikes Brace & Limb

480-981-7393 / www.fikesnet.com
6343 E. Main St., #B-1, Mesa, AZ 85205

Fine Fittings

623-214-3324 / www.fikesnet.com
18795 N. Reems Rd., Shop G-113, Surprise, AZ 85374-8685

Hanger Prosthetics and Orthotics, Inc www.hanger.com/locations

13065 W. McDowell, Avondale, AZ 85392	623-535-1919
1401 N. 51st Avenue, Glendale, AZ 8530685392	623-977-2221
932 W. Southern, Mesa, AZ 85210	480-962-6976
1032 E. Southern, Suite 101, Mesa, AZ 85204	480-461-1940
16620 N. 40th St., Bldg F, Phoenix, AZ 85032	602-765-0207
1641 E. Osborn, #4, Phoenix, AZ 85016	602-264-0097
9023 E. Desert Cove, #2, Scottsdale, AZ 85200	480-614-8820
3501 N. Scottsdale Rd., Ste 101, Scottsdale, AZ 85251	480-945-1929
13203 N. 103rd Ave, Sun City, AZ 85351	623-977-2221
13925 W. Meeker Blvd., Ste 5, Sun City West, AZ 85370	623-474-3099

Headcovers Unlimited

1-800-264-4287 or 281-334-4287




Jewel's Garden Boutique

480-412-5959
Banner Desert Medical Center
1400 S. Dobson Rd., Mesa, AZ 85202

Knitted Knockers

knittedknockers.org



Live and Give Foundation Wig Out Program

602-621-7173 / www.wiggedout.org
Provides free wigs



Mastectomy Products

602-553-0039
11001 N. 99th St., Suite #107, Peoria, AZ 85345



Pongratz Orthotics & Prosthetic


602-222-3032
2530 E. Thomas Rd., Phoenix, AZ 85016



Reba Mason of Reba's Vision

623-734-0507

Offers used wigs and prosthesis, bras and camisoles for those diagnosed with breast cancer. Also accepts donations of those products.



Scottsdale Fashion Square

480-946-4111
7055 E. Camelback Rd., Scottsdale, AZ 85251

Scottsdale Fashion Square

480-946-4111

7055. E. Camelback Rd., Scottsdale, AZ 85251



Tina's Treasures (Piper Center)

480-323-1990 or 480-323-1027 to schedule your appointment 10460 N.
92nd St., Scottsdale, AZ 85258

MAIL ORDER AND ONLINE RESOURCES

There are many other online companies.
However, if ordering a prosthesis, you should be fitted first.

TLC – Tender Loving Care

800-850-9445

Published by the American Cancer Society, this brochure includes products for women coping with breast cancer, such as bras, prostheses, swimsuits, turbans and hats.

CHAPTER 7

RECONSTRUCTION

After the natural breast has been removed, some women opt for breast reconstruction as a surgical alternative to a prosthesis or breast form. Women of all ages are finding that breast reconstruction can be a step toward restoring their bodies and their former lifestyle. Some women start reconstruction at the same time as their mastectomy; others wait several months, or even years. **It is critical for all women, even after reconstruction, to maintain breast health exams and care.**

Different approaches
to breast reconstruction include:

1

Using breast
expanders or
implants

11

Using your body's
own tissue
(autologous tissue
reconstruction)

111

Using a combination of
tissue reconstruction
and implants

Autologous tissue reconstruction, also known as tissue flap reconstruction, uses your own fat, skin, and sometimes muscle to create a breast. This procedure produces a breast that looks and moves naturally. Common tissue flaps include DIEP, GAP, latissimus dorsi, and others. Breast reconstruction is a complex procedure and should only be performed by a board-certified plastic surgeon.

There are multiple options to consider, as well as pros and cons, to having this procedure. It's essential to talk to a medical professional or health counselor.

QUESTIONS TO ASK



- What are the various types of reconstruction?
- How many of these procedures have you performed, and what is your success rate?
- When is the best time to have reconstruction?
- What type of reconstruction do you think is right for me?
- What chance is there of rejection and/or infection?
- Will an implant make it more difficult to detect a local recurrence?
- Can you show me pictures of reconstruction procedures you have done?
- Will I have a lot of pain? How can the pain be treated?
- How long will it take? What is the recovery time?
- What will the recovery be like?
- How many operations are needed?
- Can you refer me to a counselor for additional support in making a decision?

RESOURCES

American Society of Plastic Surgeons
847-228-9900 / www.plasticsurgery.org

Cancer Information Service
1-800-422-6237

National Cancer Institute
www.cancer.gov

Mayo Clinic
1-800-446-2279 or 480-301-8000 for AZ
www.mayoclinic.org

Seattle Cancer Center Alliance
<http://www.seattlecca.org>

The Breast Reconstruction Guidebook by Kathy Steglio

www.breastrecon.com

A very comprehensive guidebook on all aspects of breast reconstruction. Available from Bosom Buddies of Arizona (602-265-2776) or can be ordered from www.amazon.com or any bookstore.

www.webmd.com

www.breastcenter.com

The Center for Restorative Breast Surgery was established to serve as a dedicated resource for women seeking the most advanced methods of breast reconstruction that utilizes the body's own tissue.

CHAPTER 8

LYMPHEDEMA

Lymphedema occurs in some breast cancer patients after the removal of lymph nodes and/or radiation. It is an interruption in the lymphatic system, which filters lymph fluid through nodes into the bloodstream. When the system is altered the lymphatic fluid moves very slowly and accumulates in the affected areas, causing swelling (a.k.a. edema). There is no existing cure for lymphedema, but it can be controlled with diligent care of your affected limb. The treatment focuses on minimizing and controlling the swelling.

Some treatments include exercise, wraps, massage or compression. None of these treatments should be conducted unless they are under the direction of a physician, lymphedema therapist, and/or physical therapist.



QUESTIONS TO ASK

- How do I know if I have lymphedema?
- Whom should I call if I exhibit symptoms of lymphedema?
- What exactly is lymphedema?
- How is lymphedema treated?
- Which treatment is right for me?



RESOURCES

National Lymphedema Network (NLN)

1-800-541-3259 / www.lymphnet.org

Founded in 1988, this internationally recognized non-profit organization provides education and guidance to lymphedema patients, health care professionals, and the general public by disseminating information on the prevention and management of primary and secondary lymphedema. The NLN is supported by tax-deductible donations and is a driving force behind the movement in the U.S. to standardize quality treatment for lymphedema patients nationwide. In addition, the NLN supports research into the causes and possible alternative treatments for this sometimes incapacitating, long-neglected condition.

Lymph Notes

www.lymphnotes.com

Online resource and support for people with lymphedema, including their families, friends, and the therapists who care for them.

Banner Desert Medical Center Lymphedema Clinic

623-888-3502

Encompass Health Rehabilitation Hospital of Scottsdale

480-551-5454

Encompass Health Rehabilitation Hospital of Scottsdale

480-551-5454



Outpatient Scheduling

480-551-5436

9630 E. Shea Blvd., Scottsdale, AZ 85260



Virginia G. Piper Cancer Center

480-323-1233

10460 N. 92nd St., Suite 203, Scottsdale, AZ 85258

Many of the hospitals in the county will have lymphedema programs. See the section on Breast Cancer Centers in this guide. In addition, there are many physical therapy facilities throughout the county. Ask your physician for a referral and a prescription. The therapist should be qualified to perform manual lymphatic drainage therapy.

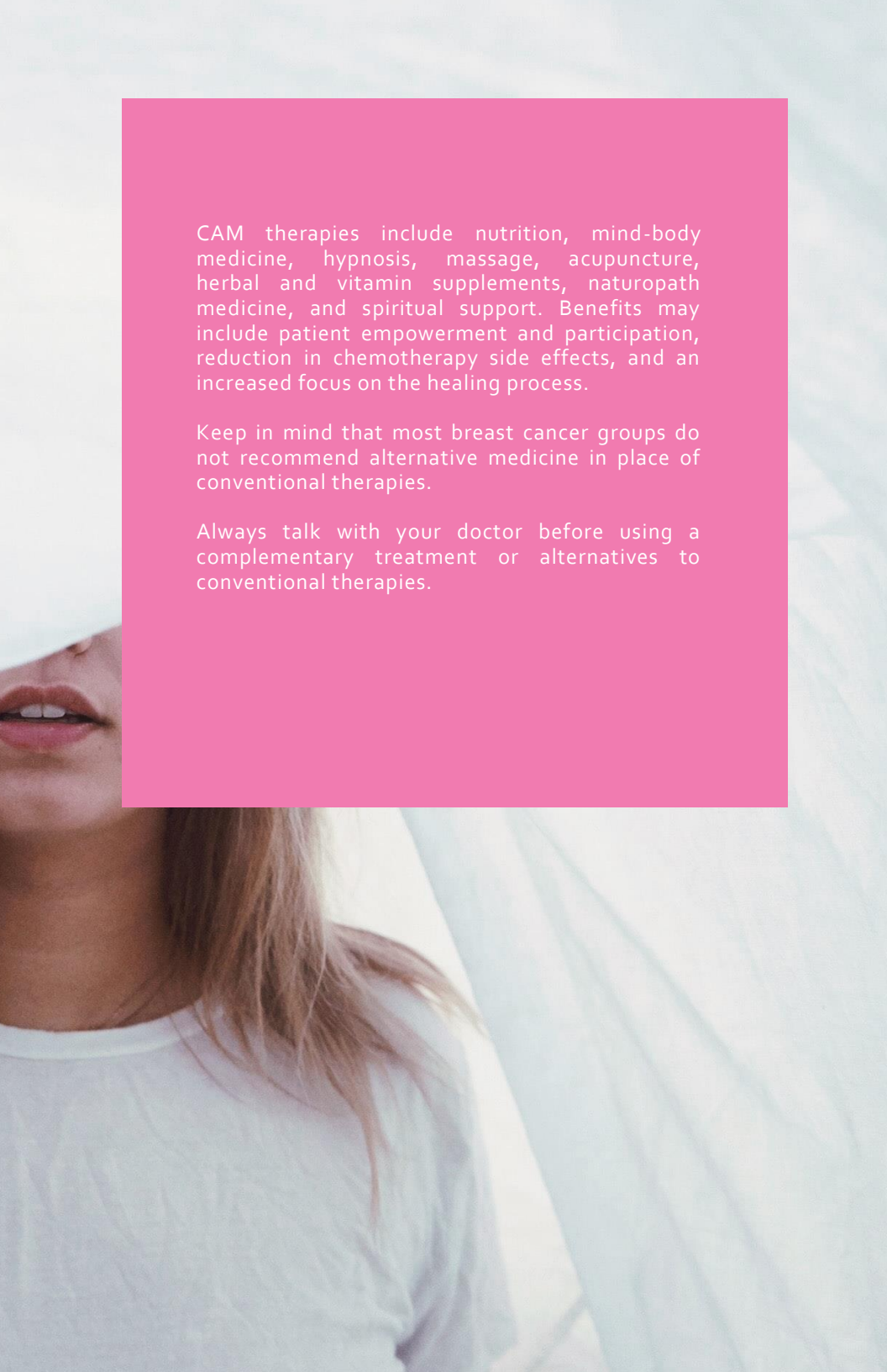
CHAPTER 9

COMPLEMENTARY AND INTEGRATED HEALTH (NCCIH)

According to the U.S. National Center for Complementary and Integrated Health (NCCIH), complementary and alternative medicine (CAM) is a group of diverse medical and healthcare systems, practices, and products that are not presently considered to be part of conventional medicine. Complementary medicine is used together with conventional medicine, while alternative medicine may be used in place 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 conventional medical practitioners are also practitioners of NCCIH.

These therapies are used to promote wellness, manage symptoms associated with cancer and its treatment, or even to treat the cancer itself. While there have been some studies of complementary therapies, most have not undergone rigorous clinical testing. Therefore, the efficacy of such therapies cannot be guaranteed. When properly combined with standard cancer treatments, some complementary therapies can enhance wellness and quality of life. However, others may be harmful during or after treatment for cancer.



CAM therapies include nutrition, mind-body medicine, hypnosis, massage, acupuncture, herbal and vitamin supplements, naturopath medicine, and spiritual support. Benefits may include patient empowerment and participation, reduction in chemotherapy side effects, and an increased focus on the healing process.

Keep in mind that most breast cancer groups do not recommend alternative medicine in place of conventional therapies.

Always talk with your doctor before using a complementary treatment or alternatives to conventional therapies.

QUESTIONS TO ASK



- Are CAMs widely used?
- How are CAM approaches evaluated?
- Are these therapies covered by insurance?
- What are the benefits of a specific therapy?
- What are the risks?
- What are the side effects?
- Will it interfere with my conventional treatment?
- Is this therapy part of a clinical trial? If so, who is sponsoring it?
- How safe are the herbal, dietary and nutrient products?
- Can there be adverse effects to acupuncture or other manipulative treatments?

RESOURCES

Annie Appleseed Project

www.annieappleseedproject.org

Provides information, education, advocacy, and awareness for people with cancer and their family and friends who are interested in complementary or alternative medicine and natural therapies from a patient's perspective.

M.D. Anderson Cancer Center's 1-877-mda-6789

Complementary/Integrative Medicine Education Resources (CIMER)


www.mdanderson.org/departments/cimer

CIMER aims to help patients and physicians decide how best to integrate CAM into their care.

Memorial Sloan Kettering Cancer Center

www.mskcc.org/mskcc/html/11570.cfm

This site provides evidence-based information about herbs, botanicals, supplements, and more.




The National Cancer Institute

1-800-422-6237 / www.cancer.gov

The National Cancer Institute and the National Center for Complementary and Alternative Medicine teamed up to publish important information on the subject (enter "CAM" in search bar).


The National Center for Complementary and Integrated Health

This is the federal government's lead agency for scientific research on complementary and alternative medicine (CAM). They provide information about CAM therapies to help patients make informed decisions about using such therapies during and after treatment. It's one of the 27 institutes and centers that make up the National Institutes of Health (NIH) within the U.S. Department of Health and Human Services. www.nccam.nih.gov



The Center for Mind-Body Medicine


www.cmbm.org



Mixtures Pharmacy and Compounding Center


480-706-0620 or www.mixturesrx.com

6515 S. 40th St., #123, Phoenix, AZ 85048



www.breastcancer.org

"Your lifeline to the best medical information about breast cancer." A comprehensive site that includes information about CAM.



CHAPTER 10

CLINICAL TRIALS

Clinical trials – also known as prospective trials – study new treatments by testing them between different groups. One group of subjects gets the treatment, while another group, the control group, doesn't get the treatment (though when there is an existing standard treatment, one group will receive that). If the new treatment is a new drug and nothing currently exists like it, the other group will receive a placebo. These studies can be randomized, where a computer picks each subject's treatment, or double-blind, where neither the researcher nor the subject know who's getting the treatment.

Prospective randomized, double-blind studies have the fewest potential flaws.



QUESTIONS TO ASK



- Should I consider participating in a clinical trial?
- What is the focus of the study?
- Which trial is right for me?
- How is the trial conducted?
- What is involved? Tests? Treatments? Time?
- Who will manage my care while I'm in a clinical trial?
- Is there any cost to me for my participation in a clinical trial?
- How much time am I required to give?
- What drugs will I be receiving?
- Will I know if I am given a placebo or the active treatment?
- If I am not given any treatment (e.g. placebo) how will I get better?
- How long will the treatment last?
- Can I stop participating in the trial at any time?
- What are the possible side effects to the treatment studied?
- Are there any risks?
- What are the advantages and disadvantages in participating?

RESOURCES

American Cancer Society

1-800-303-5691 / www.cancer.org

Breast Cancer Trials

1-415-476-5777 / www.breastcancertrials.org

Center Watch Clinical Trial Listing Service

1-866-219-3440 / www.centerwatch.com



ClinicalTrials.gov

www.clinicaltrials.gov

A registry of federally and privately supported clinical trials conducted in the United States and around the world. Provides information about a trial's purpose, who may participate, locations, and phone numbers for more details. This information should be used in conjunction with advice from health care professionals

Mayo Clinic

1-507-538-7623 or 1-800-664-4542 / www.mayoclinic.org



National Comprehensive Cancer Network

1-215-690-0300 / www.nccn.org



National Cancer Institute

1-800-422-6237 / www.cancer.gov



National Library of Medicine (NLM)

www.clinicaltrials.gov

A registry of federally and privately supported clinical trials conducted in the United States and around the world. Provides information about a trial's purpose, who may participate, locations, and phone numbers for more details. This information should be used in conjunction with advice from health care professionals

American Cancer Society

1-800-227-2345 / www.cancer.org

Young Survival Coalition

1-877-YSC-1011 / www.youngsurvival.org



CHAPTER 11

SUPPORT GROUPS AND SERVICES

Support groups offer the chance to openly discuss your thoughts with others who are going through the same experience that you are. Some studies have shown that women who attended support groups reported less depression, anxiety and pain, and even lived longer. Groups vary in size, scope and status, can be in person or online, and are directed toward patients or caregivers. Ask your doctor if there is a support group available through your local hospital or contact one of the groups listed below. Sharing, learning, listening, and talking about your experiences will help ease you along this journey of breast cancer. Remember that it's not a sign of weakness to join a support group.

QUESTIONS TO ASK

- How often do you meet? When? Where?
- May I bring along my partner, a friend, or my caregiver?
- How does this group work?
- Is there an educational component?
- Do you have a professional counselor?
- Are there trained facilitators?



LOCAL AND NATIONAL SUPPORT GROUPS

African American Breast Cancer Alliance

612-462-6813 / www.aabcainc.org

The AABCA is dedicated to providing hope, awareness, education, emotional, and social support to breast cancer survivors, their family members, and the community.

American Cancer Society

1-800-ACS-2345 / www.cancer.org

Group support at locations throughout the county and online as well. These forums provide discussion about various aspects of the cancer experience such as diagnosis, treatment, relationships, and daily living with cancer.

Reach to Recovery, one-on-one support/visitation:

1-800-227-2345

Bosom Buddies of Arizona

602-265-2776 / www.bosombuddies-az.org

Provides breast cancer support groups, educational materials, and advocacy for residents of Maricopa County. Support group meetings are held monthly at various locations throughout the county.

Breast Buds

480-657-0500 / www.breastbuds.org

Monthly meetings held in Glendale and Scottsdale.

Cancer support Community Arizona (formerly known as The Wellness Community Arizona)

602-712-1006 / www.cscaz.org


360 E. Palm Lane, Phoenix, AZ 85004

Provides a variety of programs and services for all types of cancers.

Cancer Care

1-800-813-4673 / www.cancercare.org

Provides free, professional support services to anyone affected by cancer. Offers individual counseling and professionally supported groups.



Caring Bridge


www.CaringBridge.org

Website to connect family and friends.

Celebrating Life Foundation

1-800-207-0992 / www.celebratinglife.org

A non-profit organization devoted to educating the African-American community and women of color about the risk of breast cancer, encouraging advancements in the early detection or treatment, and improving survival rates.



Centro Médico Regional de Casa Grande

1-520-381-6300


Grupo de apoyo para pacientes con cancer / Support group for individuals with cancer and their families.

1800 E. Florence Blvd., Casa Grande, AZ 85222

ChemoAngels.com


chemoangels@yahoo.com

Matches cancer patients with “angels,” individuals who help patients through treatments with small cards, gifts, and other positive graces.



FORCE-Facing Our Risk of Cancer Empowered www.facingourrisk.org

National non-profit organization dedicated to improving the lives of individuals and family affected by hereditary breast and ovarian cancers.



Happily Ever After League

1-480-275-0613

Supporting moms through cancer recovery.

Happily Ever After League

1-480-275-0613

Supporting moms through cancer recovery.



Inflammatory Breast Cancer Research Foundation


1-877-786-7422 / www.ibcresearch.org

Dedicated to the advancement of inflammatory breast cancer research in order to find its causes and increase the effectiveness of its treatment. The organization also focuses on increasing the awareness of IBC symptoms, to lead to earlier and more efficient clinical methods of detection and diagnoses.

Living Beyond Breast Cancer

1-610-645-4567 / 1-888-753-5222 (helpline) / www.lbbc.org

A national education and support organization, LBBC aims to improve quality of life and help women make sound choices about health care to help manage breast cancer diagnosis, treatment and beyond.



Men against Breast Cancer

1-866-547-MABC / www.mbcn.org

Support services targeted at educating and empowering men to be effective caregivers when breast cancer strikes a female loved one. This organization mobilizes men to be active participants in the fight to eradicate breast cancer as a life-threatening illness.



BCMets.org

Online resource that offers support and information for women living with advanced breast cancer and their families.

BrainMetsBC.org

www.brainmetsbc.org

A web site offering women with metastatic breast cancer and their families resources to learn about brain metastases from patient perspective.



Native American Cancer Network

1-800-537-8295 / www.natamcancer.org

A community-based American Indian non-profit resource that seeks to help reduce cancer incidence and mortality in Native Americans.

Nueva Vida

1-866-986-8432 / www.nueva-vida.org

Nueva Vida helps guide Latina breast and cervical cancer patients through their interactions with the healthcare system to obtain life-saving treatments.

SHARE: Self Help for Women with Breast or Ovarian Cancer

844-275-7427 / www.sharecancersupport.org

Offers survivor-led support to those affected by breast or ovarian cancer. Survivors help others address the many emotional and practical issues that arise from a cancer diagnosis. Services include hotlines in English and Spanish with capacity in 12 other languages.

Susan G. Komen for the Cure

1-877-465-6636 / www.5Komen.org

The Susan G. Komen for the Cure Breast Cancer Foundation is a leader in the fight against breast cancer through its support of research and community-based outreach programs.

Triple Step toward the Cure

1-424-258-0313 / www.triplestepowardthecure.org

General and financial support for women diagnosed with triple negative breast cancer.

Triple Negative Breast Cancer Foundation

1-646-942-0242 / www.tnbcfoundation.org

Devoted to finding targeted treatment for triple negative breast cancer, and helping to raise awareness, support researchers, and work for better detection, prevention, and treatment.

CHAPTER 12



SURVIVORSHIP

After you've been diagnosed with breast cancer, you welcome a new term into your life: survivorship. You can count from the day of the diagnosis, the date of surgery, the end of treatment....it doesn't matter. You are here. You are a survivor!

A diagnosis of cancer is a threat to your self-esteem, body image, sexuality, even to your survival. Life will never be the same after this diagnosis, and your consciousness will have been changed forever. Take time to grieve the loss because this process is an important first step toward the healing of the mind. Then, truly live.

The experience of breast cancer can be a powerful incentive to reorder priorities and see life from a different perspective. Make a point to find something wonderful in every task. Stop and smell the roses! Breast cancer can be a liberating experience, so do something you've always wanted to do. Adopt some healthy habits, eat better, and exercise more. You're alive – savor each day and enjoy life. Better yet, help others going through the breast cancer experience.

QUESTIONS TO ASK



- What can I do if I wake up at night worrying about my cancer?
- Will the cancer cells that may have spread to other parts of my body start to grow when I stop taking chemotherapy?
- What can I do when I feel excessively tired?
- Why have I lost interest in intimate relations with my partner?
- Why can't I sleep, relax, or feel interested in anything?
- Why can't I stop feeling that I am going to die because of my cancer?
- What can I do for my children, who worry not only about me, but also about themselves?
- What can I do for my children and family to help them with their reaction to my condition?

RESOURCES

American Cancer Society

1-800-ACS-2345 / www.cancer.org

Retreats and camps designed to give cancer survivors and family members of various age groups (children, siblings, adults) an uplifting and refreshing break away from the daily issues that are a part of living with cancer.

Inflammatory Breast Cancer Research Foundation

877-stop-ibc / www.ibcresearch.org

Dedicated to researching the cause of Inflammatory Breast Cancer (IBC), which is an advanced and accelerated form of breast cancer usually not detected by mammograms or ultrasounds. Inflammatory breast cancer requires immediate aggressive treatment with chemotherapy prior to surgery, and is treated differently than more common types of breast cancer.

Living Beyond Breast Cancer

1-888-753-5222 / www.llbc.org

Provides information, education, a 24/7 helpline, and one-on-one support.

National Coalition for Cancer Survivorship (NCCS)

www.canceradvocacy.org / 1-877-633-7937

This support source for cancer patients and their families provides a national network, clearinghouse, and advocacy group for anyone concerned with survivorship.

Native American Breast Cancer Survivor's Network

1-800-537-8295 / www.natamcancer.org

Helps Native Americans who are dealing with breast cancer within their families become connected to each other for a telephone or in-person support system.

National Breast Cancer Foundation, Inc.

www.nationalbreastcancer.org

An online gathering place to search for information and find support from others that are on the same journey.

Susan G. Komen for the Cure

1-877-GO KOMEN / www5.komen.org

A well-known sponsor for numerous survivor events.

Young Survival Coalition

1-877-YSC-1011 / www.youngsurvival.org

CHAPTER 13

ADVOCACY

There are several kind of cancers, and each is deserving of research dollars. Breast cancer advocates have been successful in their efforts to raise research dollars, which then leads to more researchers, more advances, more therapies, more publicity, and more survivors. As a result there have been systemic changes at the federal level in how the nation researches, finances, and delivers quality cancer care.

QUESTIONS TO ASK

- How can I affect legislation?
- How do I participate?
- What can I do to help?
- Who are my federal, state, and local legislators?
- To whom do I write/call?



RESOURCES

National Breast Cancer Coalition

1-800-622-2838 / www.stopbreastcancer.org

Since 1991, the National Breast Cancer's trained advocates have lobbied at the national, state and local levels for public policies that impact breast cancer research, diagnosis, and treatment. They are a grass-roots advocacy effort, with hundreds of member organizations and tens of thousands of individual members. Together everyone works toward increased federal funding for breast cancer research, and collaboration with the scientific community. This helps implement new models of research, improve access to high-quality health care and breast cancer clinical trials, and expand the influence of breast cancer advocates in all aspects of the breast cancer decision making process. To achieve their mission of ending breast cancer, they focus on three goals: research, access, and influence.

American Cancer Society Cancer Action Network (ACS CAN)

www.cancer.org

This is a non-profit, non-partisan sister advocacy organization of the American Cancer Society. ACS CAN is dedicated to eliminating cancer as a major public health problem through voter education and issue campaigns, aimed at influencing candidates and lawmakers to support laws and policies that help people fight cancer. (Not specific to breast cancer.)

Breast Cancer Prevention Partners

1-866-760-8223 / www.bcphp.org

The Breast Cancer Fund is the leading national organization focused on identifying the environmental causes of breast cancer and preventing the disease. They advocate for environmental health policies that place the public's health first, and work to secure the institutional changes and legislative reforms to help end breast cancer.

Mautner Project,

Whitman-Walker Health 1-202-797-3590 www.whitman-walker.org

Their mission is to offer affirming community-based health and wellness services to all with a special expertise in LGBTQ and HIV care. We empower all persons to live healthy, love openly, and achieve equality and inclusion.

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National Coalition for Cancer Survivorship (NCCS)

1-877-622-7937 / www.canceradvocacy.org

The National Coalition for Cancer Survivorship is the oldest survivor-led cancer advocacy organization in the country. NCCS believes in evidence-based advocacy for systemic changes at the federal level in how the nation researches, regulates, finances and delivers quality cancer care, and empowers survivors. They also organize Cancer Advocacy Now!™; a legislative advocacy network that engages constituents across the country in federal cancer-related issues. Patient education is also a priority for NCCS, as they believe that access to credible and accurate patient information, such as NCCS's award-winning Cancer Survival Toolbox®, is key to demanding and receiving quality cancer care. (Not specific to breast cancer.)

Susan G. Komen for the Cure

1-877-GO-KOMEN / www.komen.org

Through Komen Champions for the Cure™, the power of activism is used to achieve important legislative objectives at federal, state and local levels. They cultivate and maintain strong relationships with decision-makers and community leaders, encouraging their active engagement in the breast cancer movement.

GLOSSARY

Axilla: The armpit.

Axillary Lymph Nodes: The lymph nodes in the armpit.

Axillary Lymph Node Dissection: The surgery needed to remove some of the lymph nodes from the armpit.

Benign: Not cancerous.

Bilateral: Involving both sides, such as both breasts.

Blood Cell Count: A test that measures the number of red blood cells (RBC's), white blood cells (WBC's), and platelets in a blood sample.

Biopsy: The surgical removal of a piece of tissue to determine if cancer cells are present.

Bone Marrow: Soft cell tissue in center of the bones where blood is manufactured.

Bone Scan: A complete body exam using radioactive tracers to determine if there is any sign of cancer in the bones.

BRCA1: A gene on chromosome 17 that normally helps to suppress cell growth. A person who inherits certain mutations (changes) in a BRCA1 gene has a higher risk of getting breast, ovarian, prostate, and other types of cancer.

BRCA2: A gene on chromosome 13 that normally helps to suppress cell growth. A person who inherits certain mutations (changes) in a BRCA2 gene has a higher risk of getting breast, ovarian, prostate, and other types of cancer.

Brachytherapy: Implantation of radioactive seeds.

Breast Conserving Surgery: Lumpectomy, or a partial mastectomy, where only a portion of the breast tissue is removed, leaving the breast intact. This is usually followed by radiation treatment (and sometimes chemotherapy).

BSE: Breast self-exam by palpation (touch) or observation.

Calcifications: Calcium deposits in the breast, which can be benign or malignant.

Cancer: Uncontrolled growth of normal cells, also called malignant neoplasm or malignancy.

Cancer Cell: A cell that divided and reproduced abnormally.

BSE: Breast self-exam by palpation (touch) or observation.
Calcifications: Calcium deposits in the breast, which can be benign or malignant.

Cancer: Uncontrolled growth of normal cells, also called malignant neoplasm or malignancy.

Cancer Cell: A cell that divided and reproduced abnormally.

Carcinogen: Any substance that initiates or promotes the development of cancer.

Carcinoembryonic Antigen (CEA): A blood test for women with metastatic (widespread) cancer that can help determine if treatment is effective. Not used for screening.

Carcinoma: Cancer arising in the epithelial tissue (skin, glands, and lining of internal organs). Most cancers are carcinomas.

Catheter: A tube used to allow fluid to pass into or out of the body.
CBC: Complete blood count.

Cell: The basic structural unit of life—all living matter is composed of cells.

Chemotherapy: Treatment by chemicals or drugs that has the ability to destroy cancer cells.

Clean Margins: A margin of cancer-free tissue without invasive cells.

Clinical Breast Exam: A breast exam performed by a medical professional.

Clinical Trial: The scientific evaluation of the means to prevent, detect, diagnose, or treat disease in human beings. These are conducted after experiments on animals display evidence of potential effectiveness and preliminary studies in humans suggest usefulness.

Combination Chemotherapy: Treatment consisting of the use of two or more chemicals to achieve the most effective results.

Computerized Axial Tomography Scans (CAT Scan): Commonly called CT scans; they are specialized x-ray studies that show internal organs and can find cancer or metastases. Except for injection of a dye (used in some but not all cases), this is a painless procedure.

Core Biopsy: Removal of a piece of tissue using a needle with the use of a local anesthetic.

CSF (Colony Stimulating Factor): A growth factor that can be used to stimulate the bone marrow into making more blood cells. Cyst: Sac-like structure filled with fluid.

Cytology: Study of cells under a microscope.

DNA: One of two nucleic acids (the other is RNA) found in the nucleus of all cells. DNA contains genetic information on cell growth, division, and function.

Doubling Time: The time required to double the number of cells in a group of cells or in a tumor. A short doubling time (under 100 days) indicates a fast-growing tumor.

Ductal Carcinoma: The name given to any type of cancer that arises in the ducts of the breast.

Ductal Carcinoma In Situ (DCIS): Ductal cancer cells that have not grown outside of their site of origin, sometimes referred to as pre-cancer.

Ducts: The channels in the breast that convey milk to the nipple.

Estrogen: A female hormone produced mainly by the ovaries that affects the generative organs and breasts.

Estrogen Receptor: Protein found on some cells to which estrogen molecules will attach. If a tumor is positive for estrogen receptors, it is sensitive to hormones.

Estrogen Receptor Test (ER ASSAY): A test done at the time of surgery on the cancer tissue to determine whether changing the hormone environment would be helpful.

Etiology: Study of the causes of disease.

Excisional Biopsy: Biopsy of an entire lump, including a margin surrounding normal tissue.

Fibroadenoma: Benign fibrous tumor of the breast most common in young women.

Fibrocystic Disease: A commonly misused term used for any benign condition of the breast.

Fine Needle Aspiration: A type of biopsy in which cells are removed from a lump using a needle and syringe.

Flow Cytometry: Method of analyzing the DNA content of a cell as to the phase of division of the cell.

Frozen Section: Tissue removed by biopsy is frozen, cut into thin slices, stained, and examined microscopically by a pathologist for immediate report to the surgeon.

Genes: Located in the nucleus of the cell, genes contain hereditary information that is transferred from cell to cell. A process called genetic engineering may be used eventually to modify heredity and correct impaired immunity.

Genetic Risk Counseling and Testing: A method to determine an individual's risk of disease that passes genetically, i.e. is inherited, (such as some breast cancers) by examining the history and genetic material (blood cells) of the family.

Genome: All of the chromosomes that form the genetic map together.
Her-2 Neu: An oncogene which, when overexpressed, leads to more cell growth. It may help determine resistance to hormone therapy or chemotherapy.

High Risk: When the chance of developing cancer is greater than normally seen in the general population. Patients may be at high risk from many factors including heredity, personal habits, or the environment.

Hormone: Chemical substance produced by glands in the body that enters the bloodstream and causes effects in other tissues.
Hormones help regulate growth, metabolism, and reproduction. Some hormones are used as treatment following surgery for breast, ovarian, and prostate cancers.

Hormone Therapy: Treatment of cancer by removing, blocking, or adding hormones.

Hot Flashes: Sudden sensations of heat and swelling associated with menopause.

Hyperplasia: Overproduction of cells.

Implant: An artificial substance used to enlarge the breast to improve appearance, or to reconstruct the breast after removal due to cancer.

Incisional Biopsy: Biopsy of a selected portion of a tumor.

Infiltrating Cancer/Invasive Cancer: Cancer which can grow beyond its site of origin into neighboring tissue. Infiltrating/Invasive does not imply that the cancer is aggressive or has already spread outside the breast; tumors can be infiltrating/invasive or non-infiltrating/noninvasive.

In Situ: "In the site of." Refers to tumors that haven't grown beyond their site of origin and invaded neighboring tissue.

Internal Mammary Nodes: Three or four lymph nodes beneath the breastbone on each side.

Latissimus Flap: Flap of skin and muscle taken from the back used for reconstruction after mastectomy or partial mastectomy.

Leukocytes: White blood cells (actually colorless), which are important for the body's defense against infection. About 250,000 to 500,000 leukocytes are present in a drop of blood from a healthy person.

Leukopenia: A decrease below the normal number of leukocytes in the circulating blood.

Lobular Carcinoma: Name given to any type of cancer that arises in the lobules of the breast.

Lobular Carcinoma In Situ: Abnormal cells within the lobule. These don't form lumps and can serve as a marker of future cancer risk.

Lobules: Milk-producing glands within the breast.

Localized Cancer: A cancer confined to the site of origin without evidence of spread or metastasis.

Lumpectomy: An excision of the tumor and a small amount of surrounding tissue.

Lymph: A clear fluid circulating throughout the body (in the lymphatic system) that contains white blood cells and antibodies.

Lymph Gland: Also called a lymph node, these glands produce lymph. They normally act to filter impurities from the body.

Lymphatic System: The tissues and organs that produce and store lymphocytes, and the channels that carry the lymph fluids.

Lymphedema: Swelling of the arm or other body part caused by a blockage in the lymph channels when lymph nodes are removed. It does not indicate cancer and can also happen after radiation treatments.

Magnetic Resonance Imaging (MRI): A painless imaging technique that uses a powerful magnet to transmit electromagnetic waves and create images.

Malignant: A tumor made up of cancer cells that continue to grow and invade surrounding tissue; cells may break away and grow elsewhere.

Mammogram: A low dose radiation x-ray technique especially designed to detect breast cancer.

Mammography: The use of x-rays to make pictures of the breast; often detects breast cancer before the lump can be felt.

Mass: A tumor.

Mastitis: Infection of the breast that's sometimes used loosely to refer to any benign process in the breast.

Medical Oncologist: A doctor who uses chemotherapy and hormones to treat cancer.

Metastasis: The spread of cancer to another organ, usually through the blood stream.

Micro-calcifications: Tiny calcium deposits that are too small to be felt in breast tissue but can be seen in a mammogram picture.

Micrometastasis: Microscopic and as yet undetectable, but presumed spread of tumor cells to other organs.

Modified Radical Mastectomy: A mastectomy which removes the breast, some of the underarm lymph nodes, and the lining over the chest muscles. The chest muscles are saved.

Needle Biopsy: A biopsy in which tissue is obtained through a specially designed needle; used as a means of confirming a clinically obvious breast cancer.

Nodal Status: Normal nodes are called negative; cancerous nodes are called positive. The number and location of positive nodes in the axilla is an indication of the risk of recurrence or metastasis.

Oncogene: Genes that, when inappropriately activated, contribute to the malignant transformation of a cell.

Oncologist: A physician who specializes in the treatment of cancer.

Oncology: The study of cancer.

Oncotype DX Assay: A 21-gene assay that provides an individualized prediction of chemotherapy benefit and 10-year distant recurrence to inform adjuvant treatment decisions in certain women with early-stage breast cancer.

Palliative Treatment: Therapy that relieves symptoms such as pain but does not alter the course of the disease. Its primary purpose is to improve the quality of life.

Pathologist: A doctor who specializes in examining tissue and diagnosing disease.

PET Scan (Positron Emission Tomography): Injection of a small amount of radioisotope that localizes into breast cancer cells. Breast cancer cells use a high amount of energy and will therefore absorb great amounts of the radioisotope. Used to determine whether breast cancer has spread to the lymph nodes or to other parts of the body.

PICC: A vascular access device inserted through the skin of the forearm, so that chemotherapy can be injected without danger of leakage under the skin, or damage to the vein.

Platelet: Small particles found in the blood necessary for blood clotting. Platelet transfusions are used in cancer patients to prevent or control bleeding when the number of platelets has been depleted by disease or as a result of chemotherapy.

Port: A vascular access device surgically inserted under the skin of the chest and connected to a very large vein, so that chemotherapy can be injected without damage to the veins.

Primary Tumor: A tumor that has been identified as the original source of the cancer.

Prognosis: A prediction of the course of disease; the future prospects for the patient.

Prosthesis: Artificial replacement for a missing body part such as a breast form.

Radiation: The treatment of disease with high-energy rays to destroy cancer cells. This type of treatment may be used to reduce the size of the cancer before surgery, or to destroy any remaining cancer cells after surgery.

Radioactive Implant: A source of high-dose radiation that is placed directly into and around a cancer to kill the cancer cells.

Radiotherapy: Treatment of cancer with high-energy radiation. Radiation therapy may be used to reduce the size of a cancer before surgery, or to destroy any remaining cancer cells after surgery. Radiotherapy can be useful in shrinking recurrent cancers to relieve symptoms.

Reconstruction: The creation of an artificial and natural- appearing breast.

Recurrence: (Local) reappearance of cancer in its original area as opposed to metastases to a different area.

Regional Involvement: The spread of cancer from its original site to nearby surrounding areas. Regional cancers are confined to one location in the body.

Remission: Complete or partial disappearance of the signs and symptoms of disease in response to treatment. The period during which a disease is under control. A remission, however, is not necessarily a cure.

Risk Factor: Anything that increases an individual's chance of getting a disease, such as cancer.

Scintimammography: An imaging procedure using radio- pharmaceuticals and a special camera to find breast cancer cells.

Screening: The search for disease, such as cancer, in individuals without known symptoms. Screening may refer to coordinated mass programs in large populations.

Second Opinion: The process of seeking the advice of another medical doctor with similar credentials to assist in the decision- making process.

Secondary Tumor: A tumor that develops as a result of metastases or spread beyond the original cancer.

Sentinel Node: The single axillary lymph node that can be examined to determine if cancer has spread beyond the breast to other lymph nodes.

Staging: An evaluation of the extent of disease, determined by the size of the primary tumor and the presence or absence of cancer cells in lymph nodes and at other body parts. A classification based on stage at diagnosis helps determine appropriate treatment and prognosis.

Stereotactic Core Biopsy: A minimally invasive, image-guided procedure that helps physicians to locate breast tissue abnormalities and obtain tissue samples for diagnosis.

Surgical Oncologist: A surgeon who specializes in treating cancer.

Tamoxifen: An estrogen blocker used in treating breast cancer.

Tissue: A collection of similar cells. There are four basic tissue types in the body, epithelial, connective, muscle, and nerve.

Tomosynthesis: Type of mammography that takes x-rays in three dimensions to make pictures of the breast; often detects breast cancer before the lump can be felt.

Tru-cut Biopsy: A type of core needle biopsy where a small core of tissue is removed from a lump without surgery.

Tumor: An abnormal tissue swelling or mass that may be either benign or malignant.

Ultrasound: A procedure that uses high-frequency sound waves to locate a tumor deep inside the body.

Unilateral: One side.

X-Ray: A type of radiation that uses low doses of x-rays to diagnose disease; high doses of x-rays are used to treat cancer. The term is frequently used to refer to the picture created with x-ray.

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