



**BATT
LING
IN NORTHERN VIRGINIA,
BREAST
CANCER VICTIMS
STILL
ARE NOT ALONE.
CANCER**

BY LEXI GRAY



During the past few decades, hundreds of nonprofits have raised billions of dollars in the name of breast cancer prevention and treatment, which has led to it becoming one of the country's most visible charitable causes. Fundraisers and events occur throughout the year, with increased efforts during October, which is National Breast Cancer Awareness Month. While breast cancer campaigns seek to decrease new diagnoses of breast cancer, the American Cancer Society predicts that in 2012, about 11,350 new cases will be diagnosed in Virginia.

For many newly diagnosed women and men, research begins with their health care provider, or with large organizations such as the American Cancer Society or Susan G. Komen for the Cure, which is the largest breast cancer organization in the country. These prominent resources provide access to online discussion boards, blogs and communities where individuals diagnosed with breast cancer are able to contact others who have been affected by the disease.

Locals searching for nearby resources and support groups will find that the Northern Virginia region is home to numerous organizations focused on breast cancer awareness and research.

The region's charity events include walks, cocktail parties, fashion shows and many other fundraisers. Yet among this plethora of resources, women who are newly diagnosed or looking for information about a specific topic may feel

overwhelmed. With an abundance of information, the newly diagnosed may wonder where to go next.

BIG ISSUES AND EVERYDAY SURPRISES

Stef Woods is a local blogger, attorney and adjunct instructor at American University who is also a breast cancer survivor and advocate. Following her diagnosis in 2010, Woods found that the larger topics of breast cancer were adequately covered, and what she needed most was guidance on the everyday issues.

"I knew how to manage the nausea and fatigue caused by the treatment," Woods says. "I was [aware] of a long list of side effects that could occur during treatment, and I was prepared for those. But I wasn't finding information about things like dealing with feelings about the changes in my appearance, or how to answer peoples' sometimes awkward questions about breast cancer and treatment."

"There were a lot of surprises after I finished treatment," Woods adds. "For instance, I hadn't realized my fingernails and hair would be falling out. Even my eyelashes fell out about two months after ending my treatment. I didn't have access to information about the practical, everyday stuff. With each new annoying thing, I thought, 'Wow, it would have been nice if I had known this might happen.'"

By networking with local women who had experienced many of these same frustrations, Woods eventually found an invaluable source of information for the everyday issues related to breast can-

cer. The initial meeting for this group of women took place during a relaxed brunch event, and Woods explains she enjoys this casual approach to sharing information and stories.

“It’s very informal and very personal. The questions asked are about things we didn’t realize would be a problem, such as how to handle comments in the workplace about breast cancer,” Woods explains of the meetings. “Most people who haven’t gone through it don’t understand that the physical effects of breast cancer treatment can continue long after the final chemo or radiation session.”

CONNECTING THROUGH LOCAL SUPPORT GROUPS

Though Woods found comfort through an informal group, many resources exist for those diagnosed with breast cancer who are in search of face-to-face interactions with health care professionals, or with people like them who are battling the illness.

Eric Cohen, R.N., is the program manager for Life With Cancer, a non-profit that offers free education and



Breastfeeding

Limiting alcohol to one drink per day

Daily exercise

Maintaining a healthy weight

Smoking cessation

“A LOT OF WOMEN KEEP COMING EVEN AFTER THEIR TREATMENT, BECAUSE THEY ARE DEALING WITH SURVIVORSHIP ISSUES. THEY OFTEN FEEL AS IF ‘BREAST CANCER SURVIVOR’ IS THEIR NEW IDENTITY . . .”

support programs to members of the community. At the organization’s Dewberry Family Center in Fairfax, more than 50 classes a month are on the schedule. Class topics vary from education on how to interpret lab results to support groups, exercise programs and guidance on nutrition.

“One thing that makes us unique is that the programs are administered by oncology nurses and counselors working together,” says Cohen, who is a certified oncology nurse, and throughout his career has been drawn to the parts of his job that include patient education—for instance, teaching the newly diagnosed what to expect from their cancer treatments.

Breast cancer is the focus of several classes and programs through Life With Cancer. Several breast cancer support groups exist throughout the organization and offer either a general focus on breast cancer or a concentration on more specific populations. The typical support group at Life With Cancer has about 10-12 people at each session, according to Cohen.

Each month, a Life With Cancer support group gathers for premenopausal women who wish to discuss personal issues such as managing work and family while undergoing treatment for breast cancer. Another group exists for older women with breast cancer, and members are encouraged to discuss the challenges



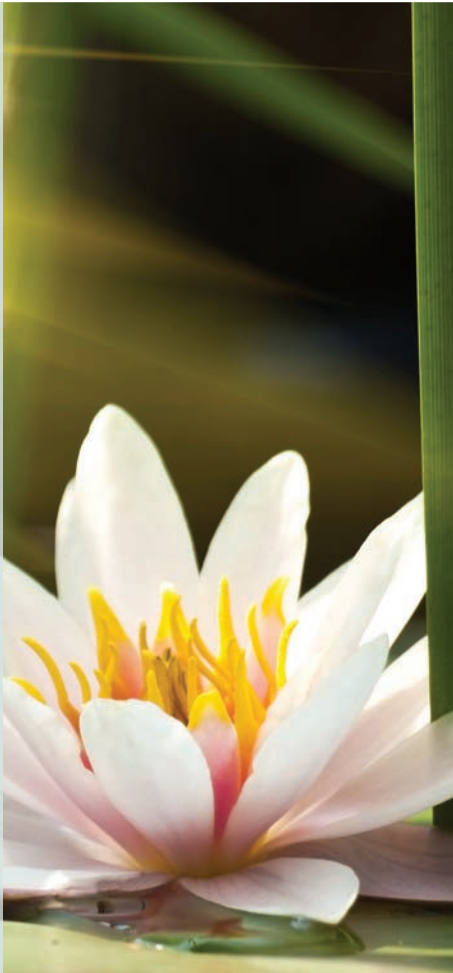
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age 40+: VISIT A HEALTH CARE PROVIDER FOR A YEARLY BREAST EXAM. FOR WOMEN WITH A FAMILY HISTORY OF BREAST CANCER OR OTHER HIGH-RISK FACTORS, ASK A HEALTH CARE PROFESSIONAL ABOUT THE NEED FOR ANNUAL MAMMOGRAMS, MRIs AND GENETIC TESTING.

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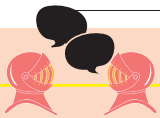
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associated with this age group. Support also exists for individuals with the BRCA1 and BRCA2 genetic markers, which are considered a hereditary risk factor for developing breast and/or cervical cancer.

Outside the support groups, Life With Cancer offers a multi-session course on breast cancer, designed for those who have been diagnosed, their family and friends, and provides information about what occurs before, during and after treatment.

Shara Sosa, L.C.S.W., is an oncology counselor at Life With Cancer who also helps to run one of its breast cancer support groups. Sosa says support groups are helpful to many people who are in search of guidance from their peers during what is often a time of difficulty and transition. Sosa, along with Miranda Gingerich, R.N., runs a once-monthly support group for young women who have breast cancer. The age limits for the group are loosely set for women ages 18-39, yet Sosa says the discussions are often more issue-based than age-based.

"We are there to answer questions and provide teaching to people about anything [that] relates to breast cancer and treatment," says Sosa. "A big focus of the group relates to concerns women have about entering menopause early



SUPPORT GROUPS/REFERRAL SERVICES

INOVA/LIFE WITH CANCER

SUPPORT GROUP FOR PREMENOPAUSAL WOMEN

Alexandria: Focuses on support and life issues. Meets the second Tuesday of each month. 703-504-7921

BRCA SUPPORT GROUPS FOR WOMEN WITH THE

BRCA GENE

Alexandria: Postmenopausal group meets the fourth Tuesday of each month. 703-504-7921

BRCA GROUP FOR WOMEN IN THEIR 20s-40s

Alexandria: Meets the second Tuesday of each month. 703-504-7921

SUPPORT GROUP FOR YOUNG WOMEN WITH NON-METASTATIC BREAST CANCER

Fair Oaks: Discussion topics include issues related to family, children and work. Meets the second and fourth Tuesday of every month. 703-698-2520

SUPPORT GROUP FOR WOMEN AGES 20-49 WITH NON-METASTATIC CANCER

Fairfax: Meets the first Tuesday of every month. 703-698-2522

SUPPORT GROUP FOR WOMEN WITH BREAST OR OVARIAN CANCER DUE TO THE BRCA GENES, OR

as a result of some breast cancer treatments. Women want to know whether they can start a family, or for those who already have children, how they can find the energy to balance it all.

“Women love having other women in their age group who can speak to the hurdles that come with battling breast cancer,” adds Sosa. The young women’s group usually has a few regulars, but attendance varies based on personal situations, and this is to be expected.

“A lot of women keep coming even after their treatment, because they are dealing with survivorship issues. They often feel as if ‘breast cancer survivor’ is their new identity and they also might have fears about recurring illness,” Sosa explains. Body image issues may also exist, especially related to mastectomy and the very personal choice of whether to undergo reconstructive surgery.

These issues are also tackled in Prince William County, where local resident Lydia Stewart helps run a support group associated with the Virginia Breast Cancer Foundation. The group meets the first Tuesday of each month at a Dunkin Donuts in Woodbridge, and each meeting begins with a prayer and a moment of silence for those who have died from breast cancer.

The Prince William meetings are intimate, with about four to eight peo-

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www.Cancer.MWHC.com

THOSE WHO CARRY THE GENE

Fairfax: Focus on education and support. Meets the fourth Wednesday of each month. 703-698-2520

GENERAL BREAST CANCER SUPPORT GROUP

Fairfax: Meets the first and third Wednesday of each month. 703-776-2813.

BREAST CANCER SUPPORT

GROUP FOR THOSE WHO HAVE FINISHED TREATMENT AND THOSE WHO HAVE HAD A RECURRENCE OF METASTATIC BREAST CANCER

Loudoun: Meets the fourth Monday of every month. Support group also exists for those newly diagnosed with breast cancer and/or starting treatment; this group meets the fourth Monday of each month. 703-858-8857

NUEVA VIDA

Washington, D.C.: Support group for Latinas with breast and/or cervical cancer at different stages; focus of group is to reduce stress, manage anxiety. Group meets the first Saturday of each month. 202-223-9100

RESTON HOSPITAL

Reston: Support group meets monthly; for women diagnosed with breast cancer

at all stages of the disease and treatment. Group tends to meet the first Wednesday of each month, but this may vary. 703-437-9595

VIRGINIA BREAST CANCER FOUNDATION

Prince William Chapter: Support group meets the first Tuesday of each month and also provides support through an extended email network. 804-285-1200

ple attending each month. An email network exists to help keep members maintain contact, even when they are unable to attend meetings.

“Members who are unable to attend the meeting receive minutes from the previous meetings, as well as updates on different events,” says Stewart. “Finding a meeting time when everyone can at-

Stewart. Men who attend and support the group do so because of females in their lives who have been affected by breast cancer.

Groups like the Virginia Breast Cancer Foundation are helpful because they play an integral role in healing, Stewart explains. “Our group provides an additional support system dedicated



SCREENING

Celebremos la Vida (METRO-D.C. AREA): Education and early detection program for medically underserved/low-income Hispanic women. 800-227-2732

Every Woman's Life (VARIOUS LOCATIONS): Breast and cervical cancer screening services for low-income women. Eligibility requirements at vahealth.org/ewl/client. 866-395-4968

Mammovan (WASHINGTON, D.C.): Mobile unit accredited by the American College of Radiology and FDA certified to perform mammograms. 202-741-3274

Sentara Digital Mammography Mobile Van (PRINCE WILLIAM): Mobile van service providing screenings for early detection. Provides information about follow-up services. For those with little or no insurance. 703-523-1999

SCREENING ASSISTANCE

American Breast Cancer Foundation (ABCF.ORG): Provides assistance with chemotherapy and medication costs. 877-323-4226

Breast & Cervical Cancer Prevention & Treatment Act Program (BCCPTA): Medical coverage for women with breast and/or cervical cancer. 866-395-4968

Breast Cancer Care Foundation (ARLINGTON): Financial assistance for individuals diagnosed with breast cancer. 703-707-9491

Karen Decker Noss Scholarship (VBCF): Recipient receives \$5,000 over 24 months to use for expenses. 804-285-1200

Tigerlily Foundation (RESTON): Coordinates meal delivery to women undergoing treatment. 888-580-6253

tend is impossible, but everyone reads the emails and lets me know when and where they can help when it comes to distributing information.”

The goal of the Virginia Breast Cancer Foundation is eradicating breast cancer through education and advocacy. “We want to make this goal a national and state priority, advocating for the collective needs of those diagnosed with breast cancer, and educating everyone in our area about this disease,” Stewart says.

The Prince William group consists of mostly women, though men are welcome and sometimes do attend, says

to seeing an end to a disease that has been around much too long.”

APPLYING FOR CLINICAL TRIALS

Clinical trials are frequently offered throughout the Northern Virginia region, due to its close proximity to federal research facilities and large university hospitals. Gaining acceptance into a clinical trial may be challenging for some, however.

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Woods recalls facing a bit of frustration during her search for breast cancer clinical trials. It didn't take long for her to discover that she did not meet the eligibility requirements for many clinical trials, due to health issues outside breast cancer and other factors.

"Once I got past the shock of having cancer, I wanted to know what I needed to do or what was even possible for me to do," Woods explains. "Clinical trials were something I had heard about, and thankfully my oncologist was very open about what was available."

Woods adds, "For those who don't have a great oncologist or access to health care resources, they might feel uncertain about how to get [clinical trial] information."

For those battling breast cancer who may be eligible, assistance navigating the many clinical trials is often provided through health care providers and local organizations. The U.S. National Institutes of Health hosts a website that publishes available clinical trials (clinicaltrials.gov). Search functions are available on the site, yet the use of medical terminology in the descriptions of each trial may prove to be a barrier for those seeking trial information.

BreastCancerTrials is one organization that will help women and men locate appropriate clinical trials that are fit for their needs. Information provided by BreastCancerTrials (breastcancertrials.org) seeks to inform the public on common related concerns. Living Beyond Breast Cancer's publication named "Guide to Understanding Breast Cancer Treatment Research Studies" is another resource that seeks to provide information about clinical trials through clear, straightforward explanations.

A common concern is that clinical trials are available only for those with metastatic cancer—cancer that has spread to parts of the body other than

**“...I
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‘WOW, IT
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where it originated. Trials are available for all stages of cancer, according to BreastCancerTrials, and also focus on issues such as screening and ongoing prevention.

Only in rare cases is a placebo given to a person diagnosed with breast cancer, as clinical trials are meant to improve outcomes not increase a person's health risks. And, a certain standard of care must be met for all participants in a clinical trial, states BreastCancerTrials' website.

www.northernvirginiamag.com 61

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Clinical trials for breast cancer are also inclusive of men, in most cases. About 80 studies either recruiting, or in the works, are accepting both men and women with breast cancer. One current trial sponsored by the European Organization for Research and Treatment of Cancer is focused solely on males with breast cancer who were treated within the past 20 years. This observational study is recruiting participants through the Anderson Cancer Center in Houston, Texas.

SPECIAL BRAS, PROSTHESES AND WIGS

Treatments and support groups provide assistance with improving inner health, yet many breast cancer surgeries and treatments cause physical changes that can be additional sources of stress. Not every woman receives reconstructive breast surgery, and the hair loss that results from chemotherapy may take years to re-grow.

Victoria LaRosa owns and operates I'm Still Me, a boutique in Warrenton that carries prostheses, wigs and bras for women during and after breast cancer treatment. The boutique is a result of LaRosa's own experiences obtaining these products, following her 2004 breast cancer diagnosis and lumpectomy.

LaRosa, along with her sister and her mother who were also battling breast cancer at the time, would visit area wig shops only to have the experience add to the stress of dealing with life as a breast cancer survivor.

TREATMENT OPTIONS

Treatment depends on the type and stage of the breast cancer, and may include any of the following:

Lumpectomy: **SURGICAL REMOVAL OF THE CANCER**

Mastectomy: **SURGICAL REMOVAL OF THE BREAST**

Chemotherapy: **TREATMENT WITH A MEDICATION OR A COMBINATION OF MEDICATIONS**

Radiation Therapy: **TREATMENT TO SHRINK AND KILL CANCER CELLS**

Hormonal Therapy: **TREATMENT THAT IS EFFECTIVE AGAINST SOME TYPES OF BREAST CANCER TO SHRINK OR SLOW GROWTH**





BREAST PROSTHESES AND ACCESSORIES

American Cancer Society (**GREENBELT, MD**): *This site has a limited supply of free breast prosthesis and mastectomy bras. 301-982-2161*

Cheryl's Health Boutique (**ROCKVILLE, MD**): *Offers personal consultations and 10-percent discounts for seniors. Mastectomy swimsuits available, in addition to lymphedema sleeves, support hosiery and more. 301-330-1084*

District Orthopedic Appliances Inc. (**FALLS CHURCH**): *Custom breast prostheses available; also bras and compression sleeves. 703-698-7373*

Dor-Ne Corset Shop (**SILVER SPRING, MD**): *Carries mastectomy bras and other lingerie; custom orders available. 301-589-5151*

Fittings by Michele (**PASADENA, MD**): *Focuses on accessories for women who have completed breast surgery, chemotherapy and/or radiation. Carries a variety of breast prostheses, bras and skin care/cosmetics. Also hosts lectures focused on women's health and wellness. 410-255-0800*

Grubb's Care Pharmacy NW (**WASHINGTON, D.C.**): *Carries bras and accessories for use following breast surgery. 202-503-2646*

I'm Still Me (**WARRENTON**): *Store will bill insurance and offers prostheses in all skin tones, bras and swimwear; discounted prices available. Evening and Sunday appointments and wigs are available. 540-878-2136*

The Medical House (**ARLINGTON**): *Ten-percent discounts are available to cancer patients. Carries breast and swimwear prostheses, and compression garments for lymphedema. 703-527-8516*

Women's and Children's Shop (**FAIRFAX**): *Has post-surgical garments, head wraps and related books. 703-776-2445*

"[The wig shop employees] sometimes refused to let you try on a wig until you made a commitment to buy it," LaRosa explains.

The stores did not accept insurance, and no one in the family was in the financial position to pay hundreds of dollars for the items they desperately needed. (LaRosa's sister had a child in college, at the time, and two more at home, while their mother lived on her late husband's veterans pension.)

"When you first get this type of diagnosis, you think the worst. You think your life is going to end," LaRosa says.

At the time of her breast cancer diagnosis, LaRosa was working in Washington, D.C., and had a long commute each day. After being diagnosed with breast cancer, she decided those precious hours spent commuting would be better spent filling the void in resources for local women.

"Every day, I prayed for guidance about what I should do. As we [LaRosa, her mother and sister] continued to notice a lack in the accessibility of breast cancer-related products, I took my retirement money and used it to open the boutique," LaRosa says.

The store has not been financially lucrative, as the bulk of income is received through insurance reimburse-

CLINICAL TRIALS*

FAIRFAX
ImClone Investigational Site:
A Study of Ramucirumab (IMC-1121B) in Combination With Eribulin Versus Eribulin Alone in Patients With Breast Cancer. 212-645-1405, clinicaltrials@imclone.com

FREDERICKSBURG
Location name : A Study of

Pertuzumab in Combination With Herceptin (Trastuzumab) And Vinorelbine in First Line in Patients With Metastatic or Locally Advanced HER2-Positive Breast Cancer. 888-662-6728

LORTON
Surgical Specialists of Northern Virginia: NBRST: Prospective

Neo-adjuvant REGISTRY Trial. 703-763-4355

RICHMOND
ImClone Investigational Site:
A Study of Ramucirumab (IMC-1121B) in Combination With Eribulin Versus Eribulin Alone in Patients With Breast Cancer. 212-645-1405, clinicaltrials@imclone.com

RICHMOND
Virginia Commonwealth University: Safety Study for Short-course Accelerated, Hypofractionated Partial Breast Radiotherapy (APBI) in Women With Early Stage Breast Cancer Using the Contura MLB. 804-828-7232

RICHMOND

ments. LaRosa says she sometimes goes months without paying herself a salary, especially when the insurance companies fail to provide reimbursement in a timely manner, or at all.

However, the financial stress of opening the boutique does not dampen LaRosa's passion for providing these products to the community. She often donates wigs, bras and prostheses to women in need, and offers second-hand items, whenever possible.

While running the store's operations, LaRosa is still continuing her fight against breast cancer.

In 2006, she had a recurrence of breast cancer that led to a full mastectomy with chemotherapy. And, this past June, two more lumps appeared.

LaRosa's sister is battling metastasized cancer, now in Stage IV.

Sadly, their mother died in 2007.

LaRosa's reward is from the steady stream of positive feedback she receives from women all over the community.

"I get letters all the time from people who are thanking me for offering [them] these products. In eight years of business I think I've only had negative feedback twice, and those were related to some type of user error, like someone wearing their wig to a barbecue and then having it get singed," LaRosa says with a laugh. 🐾



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Site: Study of IMC-18F1 or Ramucirumab DP in Combination With Capecitabine or Capecitabine on Previously Treated Breast Cancer Patients. 212-645-1405, clinicaltrials@imclone.com

WASHINGTON, D.C.
Georgetown University Medical Center: Bevacizumab,

Metronomic Chemotherapy (CM), Diet and Exercise After Preoperative Chemotherapy for Breast Cancer. 617-632-6767

WASHINGTON, D.C.
Georgetown University: A Study Evaluating INIPARIB in Combination With Chemotherapy to Treat Triple Negative Breast Cancer Brain Metastasis. 202-784-3923

WASHINGTON, D.C.

Washington Cancer Institute: Efficacy and Safety of Zoledronic Acid (Every 4 Weeks vs. Every 12 Weeks) in Patients With Documented Bone Metastases From Bone Cancer. 202-877-3061

WASHINGTON, D.C.
Lombardi Comprehensive Cancer Center/Georgetown University Hospital: Efficacy

and Safety of Zoledronic Acid (Every 4 Weeks vs. Every 12 Weeks) in Patients With Documented Bone Metastases From Bone Cancer. 202-687-2111

WASHINGTON, D.C.
Sibley Memorial Hospital: Vaccine Therapy in Treating Patients With Breast Cancer. 202-537-4000

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