



by Barbara Meyer

Aside from skin cancer, breast cancer is the most common cancer among U.S. women. According to the National Cancer Institute, it accounts for nearly 1 in 3 cancers diagnosed, reaching across a vast range of ages and socioeconomic backgrounds. Breast cancer incidence rates increase with age, with most new cases occurring in women 40 years or older; which is the age at which the American Cancer Society recommends starting annual mammograms. Women aged 20–39 are recommended to have a clinical breast examination at least every 3 years, with ongoing self-examinations. Breast cancer can strike at any age, including the twenties and even teens, and women of every age should be aware of their personal risk factors, including family history of the disease. Men can also get breast cancer.

While the subject of breast cancer has become part of our national conversation, many misconceptions still abound. For many, breast cancer is first detected as a lump, but the disease can manifest itself in other ways, such as breast tenderness, unexpected shrinking or swelling, inverted nipples, nipple discharge or bleeding, rash, or dimpling of the breast, areola or nipple that resembles the texture of an orange—all symptoms that can be dismissed as simply due to changing hormone levels. Some patients may be diagnosed with advanced stages of breast cancer after experiencing no symptoms at all.

The best ally in combating breast cancer is early detection. The purpose of early detection is to find cancers before they begin to cause symptoms. When cancers have caused symptoms, like a lump in the breast, they are more likely to have spread beyond the breast and into other parts of the body, requiring more invasive treatments. The size of a breast cancer and how far it has spread are among the most important factors in determining the scope and eventual prognosis of treatment.

While breast cancer changes an individual's life forever, that change can become a positive one, as they find and build their own inner strength and have personal and spiritual connections strengthened through their prognosis, treatment and recovery processes. The central Kentucky area has a rich network of resources for those diagnosed with breast cancer, with outstanding medical options as well as organizations providing educational and lifestyle support, all seeing exciting new strides made in the past year.



SUSAN G. KOMEN LEXINGTON—TRANSCENDING RACE BARRIERS THROUGH ADVOCACY AND EDUCATION

Susan G. Komen Lexington has launched two ground-breaking new programs to target minority breast cancer patients and those at risk for breast cancer. The pressing need to reach these women was identified in 2011, when Komen Lexington partnered with the University of Kentucky to create a community profile report. The report revealed that while the incidence rate of breast cancer is higher in Caucasian women, the mortality rate is higher among women of color, primarily due to lack of early detection. After careful development, last summer Komen Lexington launched two unique outreach programs, Colors of Promise, targeted towards African American women, and Ties That Bind (Lazos que Unen), for Latina women.

These exciting programs represent a coordinated effort to promote knowledge and deliver resources to previously underrepresented populations within Komen Lexington's 58-county service area. Using ambassadors within the communities to spread the message of awareness and prevention, they are able to take the information directly where it is needed, in a culturally effective way that the recipients will accept, understand and respond to.

Breaking Barriers to Reach Those in Need

Eileen Levy Smyth, Director of Mission and Outreach for Komen Lexington, says that while the programs allow them to better reach previously underserved cultural communities, many of the same challenges remain in combating breast cancer: educating women on risk factors, dispelling misconceptions, reinforcing the importance of early detection, and getting survivors to share their story with others and promote positive outcomes.

"When Komen Lexington began in 1982, people did not use the words "breast cancer" or discuss it openly," Smyth says. "Even within families, people didn't talk, so you didn't know that grandma had breast cancer. Now, communication is much more open, and people have a greater comfort level with discussing the topic of breast cancer with their families and friends. People see survivors in the news and at public events like 5K fundraisers, and understand through the positive messages shared that breast cancer can be overcome."

But barriers are still in place that must be tackled. Smyth hopes that increased awareness of breast cancer through the media, especially social media, will spread the word about early detection. "We want women in our community to know that what they face is preventable", she observes. "It is huge to be able to show images of breast cancer symptoms that let women actually see what to look for, and to be able to offer information in a way that's easy and free for people to get. The key to reaching women is not only to create a dialogue, but a context for a dialogue. They have to see not only what they're facing in regards to treatments, but also how breast cancer can affect their day-to-day lives and the lives of those around them. And we have to show them practical options for screening, diagnosis and treatment that they can realistically do with economic and travel limits."



"Rosa Martin is a gatekeeper to our Latina community. She is building a network of stakeholders within the area's Latina cultural base and helping us to respond to the challenges faced in getting our messages out. Many of the women are housebound and don't speak English, and there have been negative patterns of silence, denial and fear that have continually cycled through generations. In a close community, people fear the damage caused by gossip, so they keep personal information, like their health, to themselves. Often when people come to a new country, family records, including medical, are left behind, and there is nothing to refer to and no way to determine if there are genetic medical problems being perpetuated. Due to lack of statistics and barriers like language, there has been a huge population not being served, but now we have advocates like Rosa within the communities who understand the cultural norm, and how best to reach women at risk. We are thrilled to have these tireless fighters on our side!"

Komen Lexington's Mission for the Future

Komen Lexington's mission for the programs will be organizing, scheduling and hosting coalition and networking events to target the Colors of Promise and Ties That Bind communities. They'll continue to provide lectures, workshops, seminars, and health and educational fairs, maintaining contact with all outreach sites and committee members and through group and one-on-one educational activities. Another major factor is reaching out to co-survivors, the women's relatives, neighbors, church families, friends and co-workers, especially their spouses and children. In an upbeat and engaging manner, they are focusing on a continuum of care for everyone that breast cancer affects, providing them with resources for information and support. For children, it is helping to break generational



patterns and dispel cycles of helplessness and fear through education, including healthy living and understanding risk factors.

Bobbie Niehaus is a testament to the power of breast cancer survivor programs—and the power of positivity. TOPS readers first met the exuberant Niehaus when she was profiled in last year's Pink-Tober issue, and she's continuing to make her mark on Komen Lexington's Board of Directors, as their Pink Out Festival Chair.

Niehaus was diagnosed at 31 with an advanced, invasive form of breast cancer, though she had no family history of the disease. Since her successful recovery and reconstruction surgery, she's helped launch two support groups for survivors. "Stay positive, because attitude is everything," she recommends. "Having another survivor to talk to definitely helps."

With more young women opening up about their personal journeys with breast cancer and getting involved in support groups, Niehaus has noticed a new energy in the community since her own experience. She feels that having other survivors as a resource for questions and support greatly alleviates the stress and uncertainty associated with a diagnosis, and is committed to being a resource for all women, especially younger ones like herself. "As an advocate, I have met and talked with so many women," she reflects. "Speaking with newly diagnosed women makes me sad, but knowing that I have and can make a difference in their lives just makes it so worth it." She is helping to develop another program where survivors would help new breast cancer patients in person as well as on the phone.

Eileen Levy Smyth is highly optimistic about the future of all of Komen Lexington's programs, due to the strong, energetic and motivated participants who have helped Komen Lexington to establish them and are working towards their success. "I have personally and professionally grown by having these women as mentors," she says. "In the early stages of the program, I went to them. Now we work together to implement the programs and they come to us with ideas, input, and assessments of how things are working and what needs tweaking. It's our mission... it's a big mission. It can be as overwhelming to us as it is to them, but we have a really good outreach group at Komen Lexington. I bounce ideas off of them, and engage the key players locally and outside of our area. Even though I guide the programs, I rely on all of our participants to help guide me in how to best do that. None of what we have achieved would have happened without their support."

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Interested in volunteering with Komen Lexington? Please visit: susangkomenlexingtonaffiliate.volunteerlocal.com/volunteer/

MARKEY CANCER FOUNDATION

In 1978, Dr. Ben Roach and a dedicated group of volunteers had a vision for a cancer center serving central Kentucky. Since that time, the Markey Cancer Foundation (Formerly known as the McDowell Cancer Research Foundation) has donated the four buildings that now comprise the Markey Cancer Center and funded a wide variety of endowed chairs, plus numerous clinical and research programs. For the past 34 years, they have established a premier cancer center through promising cancer research programs, state-of-the-art scientific equipment, exceptional physicians and researchers, and most importantly, innovative treatments centered on the care and comfort of patients.

What the Center's NCI Designation Means to the Central KY Community

The Markey Cancer Center is Kentucky's only National Cancer Institute (NCI) designated cancer center. This signifies that the academic cancer center has achieved the highest standards of its kind and that promising cancer research that contributes directly to improved care and treatment is occurring right here in the central KY community. To patients, it offers the benefit of the most advanced care and clinical trials available without costly, time-consuming and inconvenient out-of-state travel. Two recent prestigious accreditations also attest to the Center's commitment to excellence. It earned a three-year/full accreditation designation by the National Accreditation Program for Breast Centers, one only given to those that undergo a rigorous evaluation process and review of their performance and demonstrate the highest level of patient care. It was also named a Breast Imaging Center of Excellence by the American College of Radiology, awarded to breast imaging centers that achieve excellence by passing rigorous breast-imaging accreditation programs and modules as well as the mandatory Mammography Accreditation Program.



A Team Approach to Healing

The complexity of cancer necessitates the involvement of many branches of medicine, and the Markey Cancer Center has developed a variety of specialized multidisciplinary teams to evaluate and treat the disease. This means physicians and nurses from multiple specialties working together with each individual patient to develop the best treatment plan for their individual needs.

At the Center's Comprehensive Breast Care Center, patients are evaluated by a team consisting of specialists from surgical oncology, medical oncology, radiation medicine, diagnostic mammography, pathology, and plastic and reconstructive surgery. These specialists work together in a single location to provide timely and accurate health care from evaluation and diagnostic to treatment planning. Genetic counseling and testing services are also offered, and the Center connects patients with support groups that meet on a regular basis.

The Markey Cancer Center recently expanded services offered through their Psych-Oncology suite which include Jin Shin Jyutsu relaxation therapy, nutritional counseling, and music therapy for cancer patients. Psych-Oncology also provides support for items such as transportation



to treatments, wigs for cancer patients, gas cards, lodging and assistance with other basic necessities. “We recognize that cancer takes a physical, emotional and financial toll on most patients,” says Stephanie P. Herron, President and CEO of the Markey Cancer Foundation. “We are incredibly fortunate to have community partners who work in collaboration with the Markey Cancer Foundation to provide much-needed support for patients.” Herron said that recently The Lexington Cancer Foundation donated a healing garden outside the Center where patients can soak up the sun, relax, get fresh air and take in the beauty of carefully selected ornamental plants. “It is great to see cancer patients and their family members enjoying the healing garden and we are so grateful to the Lexington Cancer Foundation for making that possible,” says Herron.

The Markey Cancer Center is the first health care provider and one of the first in the U.S. to offer tomosynthesis. This revolutionary and leading-edge technology is revolutionizing how breast cancer is detected and it is available right here in Lexington at Markey. Though it feels no different than a standard mammogram to patients, it involves multiple low-dose images that can be synthesized into a three-dimensional data set, allowing cancers to be located that might not be seen on a standard mammogram. It takes mammogram procedures to a whole new level for earlier detections and better outcomes than ever before.

Cancer often represents a long haul for the patient from the initial diagnosis, through treatment, then follow-up to maintain good health. “Beating cancer is a process, and breast cancer survivors are getting more involved than ever,” says Herron. They are active participants in recovery – both their own and that of others.” Fund-raising events and campaigns are another way to continue being involved. “More people are surviving breast cancer, which is a reflection of the impactful research and the importance of catching the disease early. Early detection is the key, and the likelihood of a successful outcome is very good for most breast cancer patients when caught early,” says Herron. To encourage more people to get screened, the Markey Cancer Center continues to expand its Cancer Prevention and Control Program across the state, offering a variety of cancer screening programs including mammograms.

“We want to be a part of making life better for breast cancer patients. This disease does not discriminate – it affects all ages, ethnic backgrounds, and socio-economic levels,” says Herron. “In response Markey keeps pushing the envelope with screenings, research, clinical trials and integrative

medicine which are all part of delivering outstanding cancer care. It is a joy to see patients who not only survive, but thrive and find renewed purpose in giving back.”

markeycancerfoundation.org | 859.323.6448

Ironcology - Persistence with a Purpose

Dr. Jonathan Feddock, a radiation oncologist at the University of Kentucky, is an accomplished triathlete and Ironman finisher who has found a highly personal way to raise awareness for cancer while helping ensure that his cancer patients receive the best treatment possible. Feddock, who specializes in the treatment of breast, gynecologic and pediatric cancers, founded Ironcology, a fundraiser to improve the treatment options at the Markey Cancer Center where he practices, by participating in the 2014 Louisville, KY Ironman triathlon race. The name reflects Feddock’s intention to combine his abilities as an Ironman athlete and as an oncologist to raise money to improve cancer care.

In order to create a new radiation suite with new equipment and a centralized treatment area, Ironcology helped defray the 1.2 million dollar cost by allowing supporters to pledge in either flat donations or by offering additional pledges for every participant that Feddock passed in the Ironman race held on August 24th. An Ironman is one of the most demanding physical challenges that an athlete can attain, consisting of a 2.4 mile swim, followed by an 112 mile bike ride, then a 26.2 mile run, all on the same day. Feddock purposely started as the final swimmer to enter the water,



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then moved through the crowd of 1,977 of the 2,095 participants, to finish 34th and 7th in his division with a final time of 9:56:22. He surpassed his own expectations by raising over \$54,000 towards the \$200,000 down payment on the brachytherapy suite.

“Similar to when I have competed in any of the triathlons that I have done previously, I constantly critique how I treat my patients and try to identify in what ways I can improve and make their treatments better. With the rapidly changing field of Oncology, it’s readily apparent that similar to triathlons, equipment upgrades that allow for more options, improved efficiency, and a safer treatment altogether are what my patients need. I decided to try and use my 2 passions in this world to improve the cancer care I can provide. Even though most would consider an Ironman to be a daunting task, it’s nothing compared to the shock and devastation that a diagnosis can bring.”

Feddock was met at the finish line of the Louisville Ironman by his family, including his wife and oldest son, as well as many other family members, friends, coworkers, and patients. He received crowd support by a tent near the finish line with the Markey Cancer Foundation, and one of his pediatric cancer patients, named Cameron, was there with entire family in tow, who were granted VIP access by Ironman and permitted to go behind the scene in the transition zones where they were able to directly participate in the race. As soon as Feddock crossed the finish line, he was first met by Cameron, his brother Conner, and their father who presented him with his finisher’s medal. Like his patients, Dr. Feddock never quits, and credits them for their example of continually striving to persevere through seemingly impossible challenges to reach their goals, as his inspiration.

Ironcology has evolved from a single event to an entire movement, as Dr. Feddock looks for other races as future opportunities to raise additional funds for the radiation suite. TOPS in Lexington would like to join The Markey Cancer Center in congratulating Dr. Feddock for his accomplishment and dedication to central Kentucky cancer patients. To learn more and find out about how you can join Dr. Feddock’s mission to help cancer patients, visit ironcology.net.

KENTUCKY CANCERLINK—REDUCING AND REMOVING THE BARRIERS TO SCREENING, DIAGNOSIS AND TREATMENT OF CANCER

What’s new for this expanding organization begins with their name. Formerly Kentucky Pink Connection, the organization’s name has been changed to reflect expanded services that go beyond the breast and cervical cancer that they originally focused on, to help people with all forms of cancer.

Executive Director Vicki Blevins-Booth created the nonprofit organization in 2008, modeled after Dr. Harold P. Freeman’s Patient Navigation Institute, to help bridge the gaps in cancer care - such as assisting breast and cervical cancer patients with transportation needs to appointments and treatments, and to help them navigate the complex and confusing health care system. Since then, Kentucky CancerLink has made a difference in the lives of nearly 4,000 patients in 117 of Kentucky’s 120 counties. Blevins-Booth was the owner of VDK Turning Point, a Lexington specialty boutique that sold products designed for women facing breast cancer, such as wigs, compression garments and mastectomy supplies.



Now the organization that she founded is able to reach out to community resources as well as provide a safety net for a variety of services to include help with medication and durable medical equipment referrals, childcare assistance, insurance referrals and other personal needs. All services are based upon funding availability.

Program Development Director Melissa Karrer knows firsthand the difference that having these assistance opportunities makes. She herself is a breast cancer survivor, starting out at Kentucky CancerLink as a volunteer helping other women benefit from her own experiences, before moving to her current position where she continues to serve on a different level. “I feel that the biggest achievement this year has been our mission expansion to serve people in our community with all cancers,” Karrer says. “We have the visible and familiar connections as we began by serving breast cancer patients, now we are proud to open up our services to help those with any cancer diagnosis. Our mission is to provide support by reducing and/or removing barriers to screening, treatment and diagnosis of cancer. The word cancer itself is universal, and the stresses are the same.”

Meeting Small Needs to Make a Big Difference

Karrer has learned a great deal from the participants who come to Kentucky CancerLink for help. “The smallest needs can make the biggest difference,” she observes. “Compression garments can help relieve the swelling and discomfort caused by lymphedema, which many breast cancer surgery patients can experience. Chemotherapy patients who have lost their hair want a realistic wig that they will feel confident wearing out. Many insurance plans do not cover wigs or lymphedema products, and many people we serve have no insurance at all. Some patients walk away from treatment because of the overwhelming financial aspect. It contributes to loss of hope. Our services help give them back that hope so that they can channel it into fighting their disease.”

“Transportation assistance is our number one request. For patients in rural areas, just getting to radiation or chemo treatments every day to the larger cities where they are provided would be impossible without assistance. Our clients are primarily those who are uninsured or underinsured and whose household income is at or below 250% of the federal poverty level. For eligible participants, we’re able to offer gas cards and arrange taxi service so that patients are able to make it to their treatment

appointments. We're able to arrange free mammograms, and hearing the word "free" takes the stress off so that those at risk are willing to move forward with necessary screening."

Through her own experience with breast cancer, Karrer feels the most important thing patients can do is not to be afraid to ask for help. "As women, we are taught to be strong and always put others first. When faced with cancer, you can look inside yourself and know that you are strong enough to do this, but that it's okay to rely on others for help. When I was initially diagnosed, I didn't always know what I needed or even how to ask for it. At first, you spend much of your time in a daze, just trying to process what has happened to you and how to go about finding things you never knew you needed, like services and support. Our organization is designed to help if you don't have a support system, to be that source you go to in your time of need. We can guide people to support groups and assist you with different steps that are new to you."

"We also reach out to their family members, surgeons, plastic surgeons and nurse navigators. By keeping an open dialogue with the medical community, we strive to make their jobs easier when cancer patients come to them. By hearing what patients are experiencing, they'll understand how better to communicate with them and have easier conversations with future patients. When you've just been diagnosed, your head is in a cloud, so having this blueprint for successful conversation where you get what you need to know helps. Having caregivers come too is important, as they are the ones who'll retain the details, while initially the patient is only hearing that they have cancer."

A Foundation of Fundraising

On October 16th, 2014, Kentucky CancerLink will be involved in BRA (Breast Reconstruction Awareness) Day USA/Kentucky Affiliate. The popular event was launched in Kentucky last year by Dr. Sandra Bouzaglou, a Lexington-based plastic surgeon, to increase awareness of the positive and empowering results of post-mastectomy reconstruction. This year, BRA Day USA is an uplifting event that encourages women to "Learn. Laugh. Live" through celebrating the BRAve Faces of Breast Cancer. Speakers will include Success Coach Julie Jones Hamilton (Learn), comedienne Leslie N. Townsend (Laugh), and local "Breast Cancer Warrior" Genea Arrasmith (Live). The event will take place at the Embassy Suites on Newtown Pike, beginning with a free educational panel discussion, open to the public, from 4:00-5:30. Panel participants include Dr. AJ (Surgeon, Baptist Health), Dr. Theresa-Anne LeVan (Plastic Surgeon, Bluegrass Plastic Surgery), Dr. Monica Hall (Plastic Surgeon, Sonata Plastic Surgery), Julie Steffey (Social Worker, Oncology, KentuckyOne Health) and 2 breast cancer survivors with the event to follow. BRA Day 2014 *Learn. Laugh. Live.* will include a



Kentucky CancerLink services include transportation assistance to and from cancer related medical appointments, lymphedema garments, post mastectomy supplies, hats and wigs.

cocktail hour, dinner, silent auction, and Embry's fashion show. Cost is \$60 per person, \$40 for breast cancer survivors. "Many women who are eligible for reconstruction don't know about their options" Karrer observes. "BRAve Faces is a national theme that helps us plug into national awareness. It shows them that life reconstructed can be about anything, life is always under reconstruction, and there are always opportunities for positive change. We're also celebrating bravery across the board, reaching out to families and caregivers, and remembering those that we've lost."

"Fundraisers like BRA Day USA are so important because they are a fun, creative, and positive way of engaging people, helping them become participants in ways that they wouldn't ordinarily be involved. They help us reach a larger demographic and show people that at the end of the day we are all a team working together to help Kentuckians with cancer. We are able to connect with caring people, companies and organizations in our community who want to use their time and money purposefully."

Karrer sees Kentucky CancerLink's history as providing a firm foundation for what she's most excited about: the organization's future growth, saying, "We'll continue to explore funding options through grants, working with community partners to sponsor events and reaching out to private donors. When we get our mission out there and it's linked with events like BRA Day USA, people know what we're doing great things and can feel confident about supporting our mission. There has been so much positive energy surrounding our organization that we want to keep growing to reach further until we can help all of the counties in Kentucky. I'm proud that we've been able to establish outreach programs that serve our community and create cancer screening awareness to Kentucky."

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While a diagnosis of breast cancer can be a person's greatest fear, the rich resources of medical expertise, support and information they'll find here in the bluegrass represent a patient's greatest hope. Central Kentucky is full of breast cancer survivors devoted to sharing their wisdom, strength, and the power of their tremendous spirits with others who are affected. If you have been diagnosed with breast cancer or have a friend or family member who has, there has never been a better time to tap into the power of our breast cancer community. As well expressed by "KY Pink Ribbon Warrior" Bobbie Niehaus, *"You have cancer – cancer does not have you!"*