



Creating a Place for Late-Stage Breast Cancer Patients

Saint Luke's Hospital's Koontz Center for Advanced Breast Cancer

The number of people living with advanced breast cancer (also known as metastatic or stage IV breast cancer) is higher than many people realize. Of the approximately 240,000 breast cancer cases diagnosed every year in the United States, 4 to 8 percent of those cases present at stage IV. That breaks down to almost 15,000 new cases of late-stage breast cancer diagnosed each year. Additionally, of the early-stage cases diagnosed each year, about 20 percent of those patients will relapse and become stage IV cancer in their lifetime. In total, nearly 60,000 women (and men) will develop advanced breast cancer each year.¹

Significant progress has been made in the treatment of advanced breast cancer, which has translated into longer survival for many stage IV patients.

The progress in advanced breast cancer, though welcome, has come despite the absence of any dedicated focus on the treatment and care of women with stage IV breast cancer. We believe that a center that brings together research, comprehensive integrative supportive services, and patient-centric care can achieve our goal of improving outcomes and enhancing quality of life for women with metastatic breast cancer.

Saint Luke's Hospital's Koontz Center for Advanced Breast Cancer is one of the only centers in the United States dedicated solely to the comprehensive care of women with late-stage breast cancer. Our singular focus is to improve outcomes and enhance the quality of life for women with stage IV breast cancer.

Recognizing the Need for Specialized Care

Timothy J. Pluard, MD, medical director of Saint Luke's Cancer Institute and a medical oncologist-hematologist specializing in breast cancer, noticed that patients presenting with advanced

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breast cancer were not receiving the same time and consideration as those who presented with early stages of the disease. Though that observation may come as a shock to many who treat all stages of breast cancer, according to Dr. Pluard, there was not the same level of attention put toward treating those with advanced breast cancer. "Treatments are getting better, and many patients are living longer with this disease," said Dr. Pluard. "However, the focus on screening and early detection of breast cancer often overshadowed the needs of women with advanced breast cancer."

To fill this void, Dr. Pluard envisioned a center dedicated to serving those who have advanced breast cancer with the goal of improving their outcomes and quality of life. The Koontz Center for Advanced Breast Cancer believes in more than just treating cancer—our team is dedicated to caring for the whole woman.

Whether you are a stage I cancer patient learning about a diagnosis for the first time or an advanced cancer patient experiencing a reoccurrence, hope plays a large part in fighting breast cancer. For advanced breast cancer patients, reaching milestones like birthdays, graduations, and anniversaries has an enormous impact on their lives and their well-being. "Like anything else, in healthcare or outside healthcare, it's about recognizing need and fulfilling that need," Dr. Pluard said.



Dr. Timothy J. Pluard meets with patient and spouse during a wrap-up consultation visit to discuss findings and subsequent plan of care.

Often these women, and sometimes men, have exhausted other resources or given up hope because they have been told by other physicians that there is nothing left to be done. Sometimes these patients are seeking a second opinion. Whatever the situation, these patients are willing to try new avenues to defeat the disease that has beaten them down emotionally and physically.

At a specialized advanced breast cancer center like the Koontz Center, treatment plans are tailored for each patient. With a focus on holistic patient-centered care, a specialized center can bring together leading-edge genomics, the most recent scientific research, medical treatments, and clinical trials, as well as the latest in integrative therapies, to create an individualized comprehensive plan for each woman.

Building the Koontz Center for Advanced Breast Cancer

In 2013, Dr. Pluard was appointed the chair of the Paul Koontz Endowment in Breast Disease at the University of Missouri–Kansas City School of Medicine. The chair was established in honor of Dr. Paul Koontz, a highly regarded retired breast surgeon with Saint Luke’s Cancer Institute. The appointment stipulated that whoever occupied the position had to research new techniques and treatment for cancer care.

During a meeting with Dr. Koontz, Dr. Pluard shared his vision of a center dedicated to serving metastatic breast cancer patients. “This was such a great opportunity and I’ve always known this center needed to be developed,” said Dr. Pluard. “If it wasn’t for Dr. Koontz, this center might still just be a vision and not a real-

ity.” The concept was accepted by the board of advisors, and the endowment was awarded. In 2015, planning began in earnest to launch the Saint Luke’s Hospital Koontz Center for Advanced Breast Cancer.

With funding in place, the Saint Luke’s Cancer Institute team began formalizing its approach to caring for women with metastatic breast cancer. Planning team members included Timothy J. Pluard, MD; Andrea Watson, BSN, nurse coordinator; Rhonda Johnson, PhD, from the Department of Psychology; Elizabeth Anderson, MS, RD, LD; Carrie Lavin, BSN, director of operations; Emily Kayrish, director of marketing; Bev Wilson, MSN, RN, ANP-BC, AOCN; Shelby Stark, BSN; Alyssa Feagans; Kathleen Johnson; and Lindsay Donlon, BSN. To begin, the team searched for an existing, similarly focused, advanced breast cancer treatment center model that it could emulate and quickly found that it was forging new ground with this concept. Though other centers offered program elements important to the treatment of metastatic breast cancer, they were unable to identify another fully comprehensive program that provided the full complement of services.

As part of the planning process, Dr. Pluard organized a series of roundtable focus group discussions with current Saint Luke’s advanced breast cancer patients and their caregivers to explore the need for specialized treatment from a patient perspective. “We knew—based on research—the elements of care that would most impact the outcomes and quality of life for women with advanced breast cancer, but we wanted to incorporate feedback from women currently living with the disease to confirm that our plans were correct.”

From these conversations, Dr. Pluard learned that many women with metastatic breast cancer pulled together their own treatment plans—generally focused on medical oncology—based on extensive online research and information shared in support groups. These women were left to figure out the integrative medicine aspects of care on their own. This finding reinforced the need for a comprehensive approach to care that incorporated both advanced medical oncology treatments and a full suite of complementary therapies.

A Holistic, Patient-Centered Approach to Design

With the goal of opening the center by late 2016, developers (architects and builders) and staff (Dr. Pluard, Andrea Watson, and Carrie Lavin) had a tight, one-year time frame to develop all aspects of the center’s physical location, from the layout and design to sourcing the technology and equipment needed for the state-of-the-art facility. “Women with metastatic breast cancer have unique needs, and we knew it was vital to create a special space just for them,” Pluard said. The planning team created a serene and tranquil environment to put patients at ease. “Part of the focus with this center is helping to relax patients when they come in the front door and to help with this, we try to make the atmosphere very spa-like.”

The Koontz Center for Advanced Breast Cancer is located within Saint Luke’s Cancer Institute—on the same floor as the Medical Oncology Clinic and across the hall from the main reception for the Medical Oncology and Gynecologic Oncology clinics. Collaboration between the Koontz Center and the Saint Luke’s Cancer Institute team is key. In fact, many supportive services including psychology, nutrition, and social work; the physicians and pharmacist in the Center for Precision Oncology; and the clinical research team are based out of Saint Luke’s Cancer Institute and utilized by the Koontz Center.

Patients are greeted in a private waiting area that boasts an additional resource room for patients and family members during their visit to the center. The clinic features three spacious exam rooms, one consultation room, and offices for the team of Koontz Center specialists.

The planning team knew that small details would make a big impact in the design of the center, choosing fixtures and finishes that would create a positive atmosphere for patients. Designers selected composite hardwood flooring, in lieu of traditional laminate or industrial tile found in most medical offices, to provide a warmer environment instead of the cold, institutional feeling of more traditional exam rooms. “Choosing flooring is a big task; you wouldn’t think it matters that much for a provider’s office, but it can mean everything for setting the tone,” said Andrea Watson, RN, BSN, OCN, clinical coordinator for the Koontz Center.

In addition to flooring, the planning team pored over details like paint colors, exam room layout, and patient robes to make sure that everything was comfortable for the patients and their families. In a traditional cancer center, patients are often handed a flimsy gown and robe when asked to undress before an examination. At the Koontz Center, plush hotel-style robes provide

warmth and comfort, helping to set the patient’s mind at ease. “It’s those small details that give this center a holistic feel, not the feel of just another clinic in another medical center,” Pluard said. Full-length mirrors in each of the exam rooms provide a place for patients to get dressed after the examination is completed—just one more patient-focused amenity often missing from more traditional exam rooms.

The center’s dual approach to care includes personalized treatments utilizing advanced genomics, immunotherapy, and clinical trials in combination with clinically proven integrative therapies, such as emotional counseling, nutrition analysis, and exercise physiology.

Finding the Way to More Efficient Care

A focus during the planning for the Koontz Center was to make patient wayfinding unnecessary. “We want this to be as easy and simple for the patient as possible.” When patients walk in the front door and check in with the receptionist, the only navigational decision is whether to sit on the couch or in a comfortable chair while waiting to be escorted back for appointments. The clinic space at the Koontz Center was specifically designed to make it easy for patients to access their care. When a patient is escorted back to the exam room, specialists come to her or him, rather than the patient having to schedule visits and find her or his way to various offices. Patients need only travel down the hall to the high-tech consultation room or to receive a chemotherapy treatment instead of going to multiple floors in a large building or visiting multiple campuses to see specialists. “We even try to bring the proper equipment in for a physical therapy visit,” said Pluard. “Many patients have said this is a completely different experience.”

The Koontz Center Care Model

The center’s dual approach to care includes personalized treatments utilizing advanced genomics, immunotherapy, and clinical trials in combination with clinically proven integrative therapies, such as emotional counseling, nutrition analysis, and exercise physiology. A diverse team of specialists focuses on the total care of patients with advanced breast cancer. Care team members include medical oncologists, psychologists, nutritionists, exercise physiologists, social workers, and spiritual health practitioners. These specialists come together to create a complete individualized care plan for each patient. No two patients are alike and no two treatment plans are alike, either.

Comprehensive Integrative Care

At the Koontz Center, treatment plans include a full menu of integrative therapies that enhance wellness, including psychology consultations, meetings with a dietitian to discuss nutritional needs, physical or occupational therapy evaluations, and social work to connect patients to additional resources available in the cancer support community. These therapies have numerous benefits on stress levels and the immune system, both of which have been shown to play a role in preventing the recurrence of cancer.² Literature suggests that incorporating integrative support into a patient's care plan improves the quality of life for stage IV breast cancer patients.³ There is also emerging evidence that these strategies can affect biologic processes that influence treatment outcomes.⁴ At the Koontz Center, we are actively conducting research into the impact of these integrative treatments.

Behavioral Health

A diagnosis of stage IV breast cancer can completely disrupt a woman's family, work, and social routines. Depression and anxiety are common. The behavioral health team at the Koontz Center helps support women and their families through this very difficult period, including assistance with the following:

- Emotional and practical aspects of a cancer diagnosis
- Quality of life issues
- Stress reduction and management
- Sleep management
- Pain management
- Anxiety and sadness.

In addition, the center hosts a support group dedicated solely to stage IV patients, allowing patients to share their concerns and their journey with peers. The support group meets monthly and is led by an oncology psychologist.

Physical Therapy

The rigors of treatment can often leave patients with advanced breast cancer feeling weak and lethargic. However, an exercise plan can help support patients' health and well-being. At the Koontz Center, a licensed physical therapist meets with patients to evaluate and identify disease-related impairments, including a reduced range of motion, strength, flexibility, tolerance, and endurance. The center also provides individualized treatment options such as the following:

- An individualized home exercise program
- A walking program to reduce fatigue
- Education regarding safety of exercise
- Functional mobility, balance, and safety training, as well as assistive devices.

Exercise after a diagnosis of early stage breast cancer has been shown to reduce risk of recurrence.⁵ However, there has been very limited study on the feasibility or benefit of exercise in women with advanced breast cancer. We are studying this by defining a personalized exercise prescription for each patient and measuring the biologic effects of exercise. We hope to determine whether

exercise can directly enhance immune response against the cancer or reduce the inflammatory state that suppresses the local immune response to the disease.

Nutrition Planning

As with exercise, nutrition has an important role in treatment outcomes. For some patients, merely maintaining adequate nutrition during treatment can be a challenge. For others, nutritional interventions may enhance treatment effectiveness. At the Koontz Center, a registered dietitian meets with each new patient to provide a personalized evaluation and provide recommendations to:

- Use nutrition to help lessen symptoms from cancer treatment
- Support strength and reduce fatigue
- Help prevent unintentional weight loss during treatment, which has been shown to improve the effectiveness of treatments
- Discuss dietary supplements.

In early-stage breast cancer, regular fasting more than 12 hours at night has been associated with a lower risk of recurrence.⁶ We are currently studying the biologic impact of fasting on women with advanced breast cancer.

Spiritual Wellness

Spiritual wellness can aid in healing and relieving stress and can be just as important during treatment as physical well-being. The Koontz Center offers patients the opportunity to meet with our spiritual health providers, who work with patients to:

- Explore their understanding of their personal spirituality
- Reflect on how their spirituality has been influenced by their diagnosis
- Discuss spiritual resources and practices
- Consider how their providers can best support their spiritual needs.

Social Services

In addition to a general psychosocial assessment to evaluate well-being and support, social service providers at the Koontz Center assess the following needs and concerns:

- Living and housing
- Finances and insurance
- Workplace/medical leave
- Medication
- Transportation
- Community resources.

The Koontz Center Approach

Prior to the first visit, the center's clinical coordinator works with patients to obtain their previous medical records, including any images and documentation necessary to give the clinical staff a full understanding of the patient's health history. During their initial visit to the center, patients meet with Dr. Pluard and the entire care team in a series of one-on-one sessions. Patients also

Dr. Paul Koontz (Center) and Dr. Timothy J. Pluard (L) receiving a donation from the Holly Ball to support the Koontz Center for Advanced Breast Cancer.



have the option of meeting with supportive services staff during this first consultation. Each specialist will assess the patient's unique treatment needs. Then, the multidisciplinary team comes together to discuss a personalized care plan for the patient. This plan may include recommendations for clinical trial participation, additional radiation or chemotherapy, or diet and exercise prescriptions, all based on the specific needs of the patient. At the end of this half-day visit, the patient receives a customized treatment plan, which incorporates the recommendations of the entire care team. "When the patient walks through our doors, they have a lot on their mind, and the idea of treatment for advanced breast cancer can be a little daunting," said Pluard. "Patients learn a lot in their first visit after meeting with the various specialties."

This unique, multidisciplinary approach is the result of careful research and planning on the part of Dr. Pluard and the Koontz Center team. "We mapped this whole process out, conceptualized it, and even did tabletop walkthroughs of the first visit," Pluard said. "Still, the first time we went through the first visit with a patient, it brought tears to the eyes of many on our clinical team, myself included. It is this level of care, commitment, and passion that makes this team exceptional."

Multidisciplinary Care Plan

After a day of meetings and assessments, the care team and patient sit down to review the plan of care. Medical information can be overwhelming. In fact, research has shown that patients, on average, retain only about 10 percent of the information shared with them during an oncology appointment.⁷ For this reason, we

encourage patients to bring a loved one with them to their consultation. We believe that it is essential for patients and families to have the opportunity to ask questions and understand the recommended treatment plan.⁸ We also offer a telehealth option so that family members who live out of town can participate in real time.

The Koontz Center consultation room is equipped with the latest Web-conferencing technology, including a high-definition camera and two large flat screens. This allows us to give a high-tech, image-rich presentation to any of the patient's family and friends who are unable to participate in person. "Having metastatic breast cancer doesn't just impact the patient," Pluard said. "This disease impacts everyone around them, and having family members hear and understand the treatment plan, as well as ask questions, is a vital component of supporting these patients."

Using Web-conferencing software, providers can open a HIPAA-compliant virtual conference room where invited participants can see the provider, images, charts, and other visuals. Patients receive a DVD copy of the entire treatment plan discussion that they can review later and share with family. The Koontz Center is also utilizing this technology to offer remote teleconsultations for patients who live out of the area or are unable to travel to Kansas City, allowing patients to access specialized treatment that may not be available in their hometown.

"The time we live in is revolutionizing the way we communicate with patients and their families," said Pluard. "Telemedicine is growing, and we are using video conferencing in other elements of healthcare and business at large. The application makes sense in this setting as well."



Koontz Center for Advanced Breast Cancer staff (L to R): Alyssa Feagans, Shelby Stark, Dr. Timothy J. Pluard, Dr. Rhonda Johnson, Andrea Watson, Andrea Edmunds, Andie Swan, Melinda Dreesman, Elizabeth Anderson.

Clinical Trials Harness the Potential for Future Breakthroughs

Research is paramount at the Koontz Center for Advanced Breast Cancer. Only through research can new therapeutic strategies be developed. With a singular focus on advanced breast cancer, the center brings the latest available research to patients.

All patients are different, and their cancers are as well. The Koontz Center uses advanced genomics to identify the unique mutations and abnormalities in each patient's cancer. The center's precision oncology physician experts understand the results of the genomic sequencing and can identify a potential treatment that works on that mutation. This allows us to find potential treatments that directly target that mutation or identify a clinical trial for that patient. Once the mutation and best treatment option has been identified, the Saint Luke's Cancer Institute team works with pharmaceutical and insurance companies to enroll appropriate eligible patients into clinical trials.

The Koontz Center partners with other academic institutions, industry leaders, and patient advocacy groups to accelerate progress in the treatment of advanced breast cancer. Clinical trials are the vehicles that ultimately lead to better treatments and improved outcomes for patients. They also offer women access to treatments not yet readily available. We strive to have a clinical trial available as a treatment option for every patient.

Remarkably, 75 percent of women with advanced breast cancer have never been asked to participate in a clinical trial, and only 5 percent actually go on a trial.⁷ Often trials can be restrictive,

limiting the number of participants or only enrolling "really healthy" patients to ensure good outcomes for the drug being tested, which hinders access to potentially beneficial treatments for advanced breast cancer patients. "The clinical trial infrastructure has not been altered in 20 years," said Pluard. "We need to make it easier for patients to get involved with these trials if that is their choice, not more difficult."

Geography can also be a barrier to clinical trial access for advanced breast cancer patients. Of the estimated 150,000 to 225,000 women living with breast cancer in the United States, many live in places too far from cities where clinical trials are most often administered and monitored. "How do we get access for those patients?" Pluard asked. "That is a question we have to answer to move the clinical trial opportunities for advanced breast cancer patients forward." Finding ways for patients to participate in trials remotely and making it easier to track results will help make these medications accessible to a larger swath of the population living with the disease, ultimately improving patient outcomes.

Another area that has widely been overlooked is the development of national standards for cancer centers specifically focused on treating patients with late-stage breast cancer. The current standards for cancer centers are focused on facilities that treat patients with the early form of the disease. A similar set of standards and inspections need to be developed for facilities dedicated to the treatment of advanced cancer. This will help elevate the level of care this subset of patients is receiving.

The Business of Advanced Cancer Care

According to Jane Peck, system director for oncology services at Saint Luke's Cancer Institute and Saint Luke's Health System, "Marketing has been extremely important to the success of the Koontz Center. There has been a heavy emphasis placed on social media and Web marketing, such as creating a dedicated Facebook page for the center, targeted Google AdWords campaigns, and paid ads on social media channels." Peck has used this approach to connect directly with the metastatic breast cancer community. Women with advanced breast cancer are heavy Internet users, spending considerable time researching treatment options and avenues for support. A digital marketing campaign reaches this patient population where they live—on the Internet.

Because the Koontz Center is the only program of its kind in the Midwest and one of just a handful in the country, marketing efforts have extended beyond Kansas City and targeted patients across a multistate region.

Peck also says that those consumers, both within and outside the Koontz Center's market, are actively searching for avenues of care and trying to find services and facilities that can help. "When you are diagnosed with metastatic breast cancer, you and your family search for answers," said Peck. "If Saint Luke's Health System isn't actively marketing the Koontz Center through digital channels, where these patients are searching, like social media networks and search engines, those patients are not going to find the answers."

In 2016, as the Koontz Center was about to open its doors, the health system dedicated significant marketing resources to promote the new facility. Saint Luke's dedicated much of its annual report to breast cancer in general, including the metastatic breast cancer patient. The emphasis has paid off, according to Peck. In the first eight months of operation, the Koontz Center for Advanced Breast Cancer had 89 new patients come in for evaluation. Of those patients, 20 percent saw the full team of advanced breast cancer specialists during their first visit and another 50 percent were evaluated by at least one additional member of the care team during their first appointment.

For Peck, one of the success stories for the Koontz Center thus far has been the high percentage of patients seeking a second opinion from the center. Currently, 45 percent of the total new patients seen in the center have come in for a second opinion. Of that new patient volume, nearly 90 percent have chosen to stay with the Koontz Center after their initial visit. "This is real, incremental growth coming from external competitors into our system," said Peck. "We are pulling patients from our competitors, and those patients are choosing to stay with us. That is huge, and it demonstrates a successful program and services provided to our patients."

The Koontz Center aims to be "the market leader and the premier provider for breast cancer treatment in Kansas City," according to Peck. "If you are diagnosed with breast cancer you are going to think of us—that is our goal."

A Vision for the Future of Care for Metastatic Breast Cancer

The Koontz Center for Advanced Breast Cancer is already attracting national attention and raising the visibility of the Saint Luke's Cancer Institute and Saint Luke's Health System. It takes visionary leadership and problem solving to make real change in an industry, and Dr. Pluard's hope is that the Koontz Center will set the tone for treatment of metastatic breast cancer.

What does Pluard envision when the Koontz Center celebrates its fifth anniversary in 2020? "I'd hope it's a leading center in the country for advanced breast cancer," he said. "Most of all, I hope the Koontz Center is improving care for women everywhere who are living every day of their lives with advanced breast cancer."

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