

NORTON CANCER INSTITUTE





our courage, our strength OUR HEROES!







With 2015 winding down, we can say with assurance that this has been a transitional year. While our high-quality, compassionate care is always at the center of what we do, we've also enhanced our ongoing research priorities, we've widened our reach into the region and we've brought on a new leader.

We believe Norton Cancer Institute is situated in a prime location for research opportunities. Our partnership with UK HealthCare's Markey Cancer Center puts us in a unique position to bring novel therapies and translational research to patients from all over our region and state. We are excited for what the future holds for our research initiatives and how it will change the face of cancer care for our patients.

UK HealthCare's National Cancer Institute designation, along with our certifications from the National Accreditation Program for Breast Centers, the Quality Oncology

Practice Initiative and the Commission on Cancer, exemplifies our mission to continually improve patient care and outcomes.

This report highlights these milestones as well as our multidisciplinary approach to cancer prevention, treatment and survivorship. These options offer hope and peace of mind to our patients and their families — the unsung heroes who touch us every day.

As one of us steps down and one of us takes the helm, we are reminded of the dedication of our physicians, nurses, clinicians and staff. They unfailingly bring their gifts and commitment to serve our patients and their families. We are honored to be a part of the world-class team that is Norton Cancer Institute.

Kuin Sharrel

Kevin S. Wardell Chief Administrative Officer Norton Cancer Institute 2000 to 2015

Joseph M. Flynn, D.O., MPH, FACP Executive Director and Physician-in-Chief Norton Cancer Institute 2015 to present

2015 achievements

Announcing a change in leadership

Joseph M. Flynn, D.O., MPH, FACP, assumed the role of executive director and physician-in-chief of Norton Cancer Institute in November 2015. Dr. Flynn succeeded Kevin S. Wardell, who is retiring after 13 years with Norton Healthcare

Dr. Flynn comes to Norton Cancer Institute from The Ohio State University, Columbus, where he held several positions including co-director, division of hematology; medical director, James Cancer Network, Arthur G. James Cancer Hospital and Richard J. Solove Research Institute; and associate professor of medicine of the university's College of Public Health.

Dr. Flynn earned his undergraduate degree from Skidmore College, Saratoga Springs, New York, a master's degree in business administration from Babson College, Boston, Massachusetts, and a master of public health degree from Uniformed Services University of the Health Sciences, Bethesda, Maryland, He earned his medical degree from the Philadelphia College of Osteopathic Medicine, Pennsylvania. Dr. Flynn has been active in community education on a wide variety of cancer-related topics and has contributed to more than 50 medical publications.

2015 Commission on Cancer survey a success



Norton Cancer Institute successfully completed its OF THE AMERICAN COLLEGE OF SURGEONS 2015 accreditation survey for the Commission on Cancer, an

American College of Surgeons program based on 34 quality care standards for comprehensive and patient-centered cancer care.

The accreditation signifies that Norton Cancer Institute is committed to offering patients a range of services, including diagnostic imaging, radiation oncology, systemic therapy, clinical trial information, psychosocial support, rehabilitation and nutritional guidance. This multidisciplinary approach leads to improved patient care and better outcomes.

Breast cancer program gains reaccreditation



ACCREDITED BREAST CENTER

Norton Cancer Institute has been granted a full three-year reaccreditation designation NATIONAL ACCREDITATION PROGRAM FOR BREAST CENTERS by the National Accreditation Program for Breast Centers (NAPBC), administered by the

American College of Surgeons. The accreditation is given only to centers that are strongly committed to providing the highest-guality breast care and undergo a rigorous evaluation of their performance.

Applicants must comply with NAPBC-established standards for treating women diagnosed with the full spectrum of breast disease. Standards include proficiency in center leadership, clinical management, research, community outreach, professional education and quality improvement.

The NAPBC is a consortium of 20 national professional organizations dedicated to improving the quality of care and monitoring outcomes of patients with breast disease.

National recognition through QOPI

Norton Cancer Institute has been recertified by the Quality Oncology Practice Initiative (QOPI) Certification Program, an affiliate of the American Society of Clinical Oncology (ASCO). QOPI certification is a three-year accreditation for outpatient hematology/oncology practices that meet nationally recognized standards for quality cancer care.

Norton Cancer Institute first achieved QOPI certification in 2011. Re-applying required participating in a voluntary comprehensive site assessment of clearly specified standards, ensuring they are consistent with national guidelines and successfully meeting the core standards and objectives of the QOPI Certification Program. QOPI is a voluntary self-assessment and improvement program launched by ASCO in 2006 to help hematology/ oncology and medical oncology practices assess the quality of the care they provide to patients.

Strengthening and expanding research

Norton Cancer Institute has a rich history of guiding clinical research. providing patients with access to important scientific advances. Our evolving partnership with UK HealthCare and the UK Markey Cancer Center, a National Cancer Institute-designated cancer center, strengthens the Norton Cancer Institute research program with the goal of improving cancer-related health outcomes for residents of Kentucky. While many of our cancer studies are industry-sponsored, Markey Cancer Center provides enhanced access to national government-sponsored trials and the data support and analysis of an academic medical center.

This relationship was facilitated by the 2014 appointment of Stephen W. Wyatt, DMD, MPH, as vice president of research for Norton Healthcare. Dr. Wyatt is a member of the Markey Cancer Center faculty and currently serves as senior associate director for the National Institutes of Healthsupported Center for Clinical and Translational Science at University of Kentucky. From 2004 to 2014, he served as dean of the university's College of Public Health and from 2000 to 2004 as the associate director for cancer control at Markey Cancer Center.

Dr. Wyatt and Norton Cancer Institute leadership are working to build on programs jointly developed between the two centers, including increasing the number of collaborative cancer clinical studies. The collaboration means physicians in cities outside of our region may be able to refer patients to Louisville rather than other metropolitan areas.

to fight cancer

Using the power of the immune system to fight cancer has been a treatment goal for many years. Over the past 25 to 30 years, drugs such as interferon, interleukin-2 and BCG vaccine have been used with generally modest success in only a few cancers. Research in the past several years has unlocked some of the secrets of the immune system and revealed why some cancers have been resistant to immune treatments in the past. Tumors have been found to produce substances that block the immune system from recognizing cancer cells as "foreign." These substances keep the immune system "in check" by preventing it from attacking the cancer. Drugs prevent these substances from hiding tumors from the immune system are often referred to as "checkpoint inhibitors." Several drugs have been developed and approved by the FDA for the treatment of melanoma. In addition, drugs are now on the market for the treatment of lung cancer after first-treatment failure.

indications.

Emerging data and research regarding these agents is prompting Norton Cancer Institute to expand clinical trials and the availability of immunotherapy to our patients.



Norton Cancer Institute has enrolled a patient in a clinical trial through the International Extranodal Lymphoma Study Group. The patient has primary mediastinal large B-cell lymphoma, a type of extranodal lymphoma. Norton Cancer Institute is the only participant in Kentucky and one of only 13 in the United States, among them M.D. Anderson Cancer Center, the University of Chicago and Columbia University Medical Center.

This unique cooperative group brings together scientists from institutions all over the world so that data can be amassed from a sufficient number of patients to study specific extranodal sites of this type of lymphoma. Although extranodal lymphomas are not rare, the frequency of involvement of any particular site is not high enough for a single institution to study and answer major questions about its treatment. The phase III comparative study is assessing the role of mediastinal radiotherapy after Rituximab-containing chemotherapy regimens.

Unlocking the secrets of the immune system

At Norton Cancer Institute in 2014, we participated in early immunotherapy trials for bladder and lung cancers. Both focused on treatment of patients in the second-line setting. The immunotherapy drug studied in our 2014 lung clinical trial is now FDA approved. The immunotherapy drug studied in our 2014 bladder cancer trial has moved into later-phase trials, with further studies currently open at our center. This immunotherapy drug is also being studied in first-line indications for renal cancer and lung cancer. Many of our current studies combine approved chemotherapy and/or biotherapy agents with these new immunotherapy drugs, in newly diagnosed metastatic patients. Other ongoing studies with immunotherapy are evaluating the drug as treatment following surgery in the adjuvant setting for multiple

International research saves more patients

Outreach services expand to seven locations

As a regional leader in cancer care for more than 20 years, Norton Cancer Institute has a long-standing tradition of excellence that is now available to even more patients across the region. The following outreach services were rolled out in additional locations in Kentucky and Southern Indiana:

- Clinics for new patients and follow-up visits
- Telemedicine consultations
- Tumor boards
- Support services

Advancing breast cancer treatment

In 2015, Norton Cancer Institute introduced two technological advances in radiation treatment for breast cancer - a new breast seed technique and a prone breast board device for improved radiation targeting in women with large breasts.

Radioactive seed aids in breast cancer surgery

In early 2015, Norton Hospital became the first health care facility in Kentucky to use a radioactive seed to mark the site of a tumor prior to breast surgery. Until now, using a thin wire was the most common way of marking a tumor site.

The new procedure is virtually painless. The implanted seed measures about half the size of a grain of rice and can be implanted up to five days before surgery. By contrast, wire insertions are performed the same day as surgery. This means patients may sometimes wait long periods holding a large cup over their breasts on the day of surgery. In addition, the localized seed placement helps the surgeon precisely find and remove the tumor, helping to spare healthy tissue.

🛞 kVue Access 360 breast board

Norton Cancer Institute now has a prone breast board device for women with breast cancer who need radiation therapy. The board significantly reduces radiation to the heart and lung. It is designed to allow treatment of the whole breast or partial breast as well as accelerated breast treatments while the patient is in the prone position to maximize separation between the breast and critical organs. This also improves the potential for more uniform dose delivery, less skin toxicity and reduced respiratory motion. The board is designed in such a way that it provides full access to the supraclavicular nodes. The kVue Access 360 is available at Norton Cancer Institute Radiation Center – St. Matthews.





Amber Neal Awake during surgery to remove brain tumor

Three years ago, 23-year-old Amber Neal was feeling the glow of her first pregnancy, anxiously awaiting the joyous event of her son's birth. But something odd and troubling cast a pall over the Mayfield, Kentucky, resident: Without warning her right eye would twitch uncontrollably, her mouth would draw up and she was unable to speak for a minute or two. These episodes occurred only four times during her pregnancy, but they were enough to send her into a tailspin.

"At first, I panicked," Amber said. "I had no clue what was causing these symptoms."

Initial testing proved inconclusive, adding to her anxiety.

Amber was told she would have an awake craniotomy, the preferred technique for performing surgery involving functionally important parts of the brain.

"It was scary," she recalled. "I felt better when I learned the brain has no pain receptors."

of life.

The successful surgery was followed by a radiation/chemotherapy regimen for several weeks. The only ill effects from Amber's surgery are a slight loss of feeling in her right index finger and thumb. The corner of her mouth may droop when she's tired. But most important, her seizures are gone. She undergoes an MRI every four to six months to check for any recurrence.

Caroline.

Logan, her precious baby boy, was born in August 2012, but she barely had the chance to cherish the first moments. Those strange seizures returned, but this time with a fury, occurring as many as 20 times a day. An MRI at Norton Neurology Services in October 2012 revealed a stage 4 brain tumor, and immediate surgery was recommended.

David A. Sun, M.D., Ph.D., neurosurgeon, Norton Cancer Institute and Norton Neuroscience Institute, performed the surgery while his colleague, Bradley S. Folley, Ph.D., neuropsychologist, asked Amber to write down selected words on a notepad as Dr. Sun stimulated an area of the brain with a mild electrical current. If the stimulation affected Amber's ability to perform the task, this area was marked as one to be preserved. This brain-mapping technique helped to ensure that the surgery did not rob her of essential brain functions such as language and memory, which would affect her quality

Throughout her unsettling ordeal, Amber has had the unwavering support of her husband, Daryl, and children, 3-year-old Logan and 7-month-old

"I'm glad I had the chance to go to Norton for treatment," Amber said. "They are totally awesome."

Community support

Creating a hopeful future for our neighbors in Indiana

Hope is what Norton Cancer Institute Resource Centers provide, along with comfort, compassion and the information families need to get support and care at every step in their cancer journey.

To Pat Harrison of Southern Indiana, it's especially important to bring hope and support to residents of her community. It was her own experience that helped shape the vision for the new Norton Cancer Institute Pat Harrison Resource Center.

After being diagnosed and treated for breast cancer in 2013, she realized cancer patients in Southern Indiana need a warm, welcoming, healing place to receive information and support services and to meet others going through the same journey. It is Harrison's hope that the resource center will be a place where cancer patients, and women in particular, can feel good about themselves.

The Norton Cancer Institute Pat Harrison Resource Center will be located in Jeffersonville, Indiana. The existing building is being remodeled and restored and will open in February 2016. The free-standing facility will have a warm and welcoming feel, a dedicated parking lot for easy access and a full-time nursing and support staff. The center will feature an atrium reception area, library/reading room, indoor and outdoor meditation spaces, individual and group meeting areas, a massage therapy center, prosthetics center and plenty of space for individuals and families to meet with a multidisciplinary team of providers. All these services are free, no matter where patients are in their cancer journey or where they receive care.

About the Norton Healthcare Foundation

Helping patients and families during and after their cancer experience is a major focus for not only Norton Cancer Institute but also the Norton Healthcare Foundation, the philanthropic arm of the not-for-profit Norton Healthcare system. In 2014 and 2015, the foundation gave more than \$1.5 million toward cancer care for a variety of programs and services.

This support would not be possible without the generosity of the community. Norton Cancer Institute relies on donations from individuals and organizations to make a difference for its services and programs. From screenings in underserved parts of our community to funding for cutting-edge clinical trials, the Norton Healthcare Foundation provides valuable resources for Norton Cancer Institute to continue its mission of hope, healing and compassion for patients and families.

Grants by the Norton Healthcare Foundation included funding for:

- Continuing education for registered nurses seeking to become oncology certified through the foundation's Oncology Education and Prevention Fund, established by the Nixon family of Louisville
- Ongoing outreach activities and peer support opportunities for young adult survivors of cancer through the Young Survivors support group
- Lifesaving screenings aboard the Mobile Prevention Center in underserved areas in our community
- Cutting edge video-conferencing technology that enables Norton Cancer Institute physicians to collaborate remotely for the benefit of patients throughout the region
- The Norton Cancer Institute Breast Health Program
- Clinical research programs at Norton Cancer Institute
- Unique partnerships with community cancer groups to provide emotional support and strength to men and women facing cancer
- Facility and equipment support for the Norton Women's & Kosair Children's Hospital inpatient cancer unit that opened in 2015

About the Children's Hospital Foundation

Norton Cancer Institute services span a lifetime, starting with children diagnosed and treated in the Addison Jo Blair Cancer Care Center at Kosair Children's Hospital. Donations to cancer care through the Children's Hospital Foundation are aimed at ensuring the hospital has the equipment and resources to provide the most specialized treatments for children with cancer.

The Children's Hospital Foundation provided more than \$350,000 in 2014 to support pediatric cancer initiatives that ensure all children diagnosed with cancer at Kosair Children's Hospital, and the hundreds receiving ongoing treatment, have access to the care they need.

Community education and awareness events

September.



about breast cancer. Proceeds from the event help women who don't have the resources to get mammograms. The muchanticipated event is an evening of shopping and Derby-themed entertainment. Since it began in 2007, Derby Divas has raised more than \$1 million to support the Norton Cancer Institute Breast Health Program, including providing mammograms for underserved women in our community. In 2015, funds from the event helped establish the Derby Divas Breast Health Center at Norton Women's & Kosair Children's Hospital.

Each year, with support from the Norton Healthcare Foundation, Norton Cancer Institute sponsors two lectureships for physicians and clinicians that are also open to the public and free to attend. The Gail Klein Garlove Lectureship and Nixon Lectureship address timely topics in cancer prevention, detection and treatment. These events are funded by the Norton Healthcare Foundation, which also supports community cancer awareness and fundraising initiatives that benefit Norton Cancer Institute. Some of these events include Derby Divas every April leading up to the Kentucky Derby and the Bike to Beat Cancer, a bicycling event held each



Derby Divas is a fundraising event held each April to kick off Derby season and to raise awareness







Now in its seventh year, the Bike to Beat Cancer is a one-day cycling event for riders of all levels to raise funds for Norton Cancer Institute. Riders can choose from three distance options or a 5-mile Family Ride through scenic Kentucky bluegrass country.

Funds raised through the event support prevention, early detection and educational initiatives at Norton Cancer Institute, as well as programs that encourage patients and families to approach cancer with a hopeful outlook. The 2015 Bike to Beat Cancer raised more than \$462,000 for adult and pediatric cancer programs. Since its inception, the Bike to Beat Cancer has raised just under \$2 million.



The Children's Hospital Foundation supports pediatric cancer services available through Norton Cancer Institute. Its main fundraising event for childhood cancer is g Kosair Children's Hospital Chili's Clip for Kids, held each May. The event challenges

participants to raise funds in return for shaving, trimming or clipping their hair in solidarity with kids fighting cancer at Kosair Children's Hospital. What makes the event unique is that every dollar raised stays in the community by directly going to Kosair Children's Hospital.

In 2015, nearly 500 people came together to help the second annual Chili's Clip for Kids event raise more than \$88,000. These funds are used to continue the comprehensive support and educational programs, advanced treatments and equipment, and research available at the Addison Jo Blair Cancer Care Center at Kosair Children's Hospital. Learn more at HelpKosairChildrensHospital.com





telltale scarf.

Maria Beck, M.D.

"My mom not only takes care of me, but she's taught me to take care of myself," Anna-Maria said. "She makes sure I wear cute pajamas when I'm in the hospital. When you look good, you feel good."

An account of what happened before a scheduled craniotomy two years ago illustrates her positivity.

the braces.

"Getting my braces off early was one of the perks of having brain surgery," she joked. And she was on that dance floor.

Maria is amazed by her daughter's vitality: "Anna really lights up a room. She's all about the positive. That's just the way she is. She's driving the whole bus, and the rest of us are just going along for the ride."

Learn about ways you can help at NortonHealthcareFoundation.com.

Anna-Maria Beck: **Positive attitude and a helping hand**

If one phrase could most accurately describe Anna-Maria Beck, 16, it would be "a whirlwind of activity." Anna-Maria, despite having had 12 brain surgeries since age 7, is a kind soul who loves helping others.

In 2014, she was named Outstanding Youth in Philanthropy by the Louisville chapter of the Association of Fundraising Professionals. That honor came in recognition of her work for childhood cancer, including serving on the Children's Hospital Foundation Bourbon & Bowties planning committee, which raised a record \$381,000 for cancer care at Kosair Children's Hospital that year.

Anna-Maria's generosity knows no bounds. She was a pen pal with a terminally ill child, exchanging dozens of emails over several months before the child passed away. On a trip to Target, she boosted the spirits of a stranger for a whole hour after recognizing the shopper was a cancer patient by a

"I love talking with people," Anna-Maria said. "I try to look on the bright side of things, to stay positive."

Living with a brain tumor since 2007, the high school junior never complains about her health, choosing instead to focus her energies on spending time with friends, singing and expressing her creativity through drawing, photography and cooking. She has learned how to stay positive from her mother,

Just before the procedure, Anna-Maria told her surgical team in Boston that she really wanted to return to Louisville for her freshman dance in two weeks. There was one snag: The braces on her teeth were interfering with the imaging tests needed before surgery could begin. The solution: Take off



Anna-Maria Beck (right) with her family



Adult cancer services

Prevention and early detection

In 2014, the Norton Healthcare Mobile Prevention Center screened more than 4.600 people for breast, cervical, colon and prostate cancers. For women who received mammograms, 13 percent had never been screened. In 16 percent of women, it had been five years or more since their last mammogram. Of the women screened in 2014, 28 had pre-cancer or cancer that was diagnosed and treated as a result of the mammogram they received on the mobile unit. Since the program's inception in 2007, 144 people have been diagnosed and treated for pre-cancer or cancer aboard the mobile unit

In 2014, the Norton Healthcare Prevention & Wellness team also screened more than 7,000 people for other health conditions, including high blood pressure, diabetes, cholesterol and osteoporosis. The team provided information about tobacco cessation, diet and exercise at the time of screening. More than 8,300 people received education during screenings in 2014. In addition, those with abnormal results received education and navigation after their screenings.

Genetic counseling

The Norton Healthcare Prevention & Wellness Genetic Counseling Services team carefully evaluates each individual's family history, conducts personal cancer risk assessments and provides guidance through the genetic testing process if needed.

In 2014, 489 new patients received hereditary cancer genetic counseling through Genetic Counseling Services. Of those, 379 electing to proceed with genetic testing and 160 were found to have a hereditary cancer syndrome. These individuals were offered several options, including observation, enhanced surveillance and surgery, depending on their desires, age, overall health and level of risk. Our team recognizes that the impact of an inherited risk for cancer extends beyond the patient being tested to include family members, some of whom also might carry the increased risk. Our counselors work in partnership with patients' physicians to provide personalized recommendations.

Treatments and services

Norton Cancer Institute is the largest comprehensive oncology practice in the region, offering medical oncology/hematology, radiation oncology, gynecologic oncology, neuro-oncology, surgical oncology, orthopaedic oncology, behavioral oncology and oncofertility services, along with the prevention, early detection and support services described in this report. Our physicians, oncology-certified nurses and staff provide advanced treatment options and offer compassionate services for patients and their families. With eight outpatient office locations, three radiation centers, seven chemotherapy infusion centers and access to numerous clinical trials, patients have world-class, multidisciplinary care right here in Greater Louisville.

Treatments and services

hospitals – Norton Audubon Hospital, Norton Brownsboro Hospital, Norton Hospital and Norton Women's & Kosair Children's Hospital.

- The latest medical. pharmaceutical and chemotherapy treatments, including oral chemotherapy
- Minimally invasive
- Radiofrequency ablation, a less invasive nonsurgical treatment to remove liver
- invasive alternative to
- the diagnosis and treatment of specific cancers, such as thyroid cancer, bone pain
- imaging; used to treat lung and brain cancers as well as many other cancerous and noncancerous conditions, such as trigeminal
- High-dose radiation highly localized radiation administered internally to

healthy tissue and reducing side effects; used to treat breast, lung and gynecologic

- used for nonresectable lung
- invasive method of breast cancer; offers a shorter treatment duration and reduced side effects
- Calypso external beam
- Multidisciplinary clinics and programs: Brain Tumor Center. Liver Cancer Program, Lung Cancer Clinic, Clinic, Genitourinary
- Tumor boards
- Private specialty pharmacy
- Oral chemotherapy program
- Three Norton Cancer Institute Resource Centers

Lymphedema services

The Norton Cancer Institute Lymphedema Program is staffed by two physical therapists and one occupational therapist who are certified in manual lymph drainage and complete decongestive therapy. Patients at risk for lymphedema are evaluated, educated on risk reduction and measured for baseline comparison. Patients with lymphedema are seen for complete decongestive therapy, including manual lymph drainage, compression therapy, therapeutic exercise, skin and nail care, and lymphedema management education. In 2014, the Lymphedema Program cared for 366 patients at its three locations.

Norton Specialty Pharmacy

Norton Specialty Pharmacy offers Norton Cancer Institute patients comprehensive and convenient pharmacy services. The pharmacy has two full-time pharmacists and two pharmacy technicians specializing in oncology and specialty medications. The pharmacists work closely with providers and patients to address any treatment issues.

Patients who use the specialty pharmacy receive their cancer medications more guickly than at other area pharmacies, where availability is often limited. This minimizes delays in treatment. Norton Specialty Pharmacy also offers personalized information about medications and financial assistance, specialized billing to Medicare Part B and Part D patients, commercial plans and options for delivery and pickup.

Breast Health Program

The Norton Cancer Institute Breast Health Program was developed to provide comprehensive breast health care, including prevention, diagnostic and treatment services to the community. Along with clinical services, the program provides education, counseling and support. A team of oncology-certified nurse navigators is specially trained in breast health issues and breast cancer treatment to assist patients and their families from the point of a suspicious finding through diagnosis, treatment and survivorship. Norton Healthcare is the first hospital network in Greater Louisville to achieve and maintain a threeyear full accreditation designation by the National Accreditation Program for Breast Centers (NAPBC), a program administered by the American College of Surgeons.

2014 data, the most current data avilable at the time of this printing, is reported herein.

Patient navigators

Norton Cancer Institute offers patient navigators for any type of cancer. These oncology-certified nurses provide assistance for patients and families from the point of screening or a suspicious finding through diagnosis, treatment and survivorship. Navigators provide the following services:

- Coordinate care and assistance to streamline appointments, allowing for more timely treatment
- Identify and assist with any barriers to cancer care, such as educational, financial, transportation, language, cultural, communication and fear
- Oversee the educational, emotional and social needs of patients and families
- Provide one-on-one education to help patients and families understand diagnosis and treatment options
- Link patients, families and caregivers to community resources to address specific needs during the cancer treatment experience
- Lead and facilitate support groups for patients and their families

Norton Cancer Institute Resource Centers

Norton Cancer Institute offers patients and their families a place to turn for support, assistance and education. Three resource centers provide personal attention to address patients' physical and emotional needs before, during and after cancer treatment. Their mission is to offer comfort as well as to educate.

The resource centers' free services include:

- Community support and Norton Cancer Institute-sponsored support groups
- Classes and seminars
- Private educational sessions with oncology-certified nurses
- Complementary therapies, including Reiki, massage, art and music therapies
- Nutritional counseling
- Wigs, turbans and hats
- Lending library with current educational information

In 2014, Norton Cancer Institute Resource Centers had more than 25.000 interactions with patients, families and caregivers.

Behavioral oncology

For many individuals, a new cancer diagnosis can bring about a wide range of emotions, including sadness, fear and worry associated with the uncertainties that come with cancer. The Norton Cancer Institute Behavioral Oncology Program offers an integrated approach to addressing the mental health and emotional aspects that often accompany cancer care. While the importance of this specialized type of care is understood, Norton Cancer Institute is one of few oncology programs nationwide offering a robust program for mental and emotional health needs.

The Behavioral Oncology Program is staffed by a team trained in psychosomatic medicine and equipped to care for the emotional and mental health needs of patients and their families and enhance quality of life. A full spectrum of services are available, including individual therapy, couples therapy, medication management and interdisciplinary collaboration.

Unresolved psychological distress can contribute to a desire for death, reduced adherence to cancer treatment, decreased quality of life, prolonged hospitalizations, increased health care costs and exacerbation of challenging caregiving needs and family dynamics. Oncology providers and the staff at Norton Cancer Institute routinely assess the emotional health needs of oncology patients and make referrals to this specialized service within Norton Cancer Institute.

The provision of the depth and breadth of supportive resources for patients and their families distinguishes Norton Cancer Institute as a leader in cancer care for the whole person. The Behavioral Oncology Program saw approximately 6,000 patient encounters in 2014.

Palliative care

Because a diagnosis of cancer and the treatment that it often involves can have a major impact on quality of life, Norton Cancer Institute is always seeking to improve the supportive services we provide. One of those important services is palliative care, which is a specialized holistic care that seeks to minimize the pain and other physical symptoms that patients can have as well as address the emotional, social and spiritual distress that can be experienced by patients and their family members.

Norton Hospital has an inpatient palliative care program to provide an extra layer of support as patients move through the various stages of treatment. This multidisciplinary team consists of a physician, nurse practitioner, nurse, social workers and chaplains. They give special attention to symptom control, clarifying the care goals and hopes of patients, and supporting patients and families spiritually, socially and emotionally. Some palliative support services, such as pastoral care and behavioral oncology, also are available at Norton Audubon Hospital, Norton Brownsboro Hospital and Norton Women's & Kosair Children's Hospital in St. Matthews.

Survivorship

Enormous strides are continually being made in cancer treatment, accounting for more and more people living with a personal history of cancer. These cancer survivors require medical care and support services tailored to meet their unique needs. The Norton Cancer Institute Survivorship Program provides a special level of care for adults with a history of cancer who have completed active therapy. Services include comprehensive clinical support, education and resources, including:

- Survivorship care plans and treatment summaries
- Clinic for adult survivors of childhood cancer
- Information on health consequences of cancer treatment
- Screening for other cancers
- Counseling for family members and caregivers
- Risk assessments
- Assistance with maintaining a long-term patient/physician relationship
- Information on new treatments and therapies

Network Cancer Registry



In order to successfully manage all cancer data throughout the Norton Healthcare system, a centralized cancer registry department was developed in 2004. The Network Cancer Registry maintains a systemwide cancer database and provides systemwide data reporting for administrative planning and research/outcomes measurements for clinicians. In 2015, the American College of Surgeons' Commission on Cancer re-accredited the Network Cancer Registry with commendations. The registry is the only program in the region with network accreditation. This level of accreditation assures that the cancer program is meeting or exceeding all cancer standards for quality improvement, creating benchmarks for clinicians and exploring trends in cancer care.

The Network Cancer Registry database contains more than 77,793 cancer cases. In response to the American College of Surgeons' Commission on Cancer cancer treatment and survivorship, expand prevention and early detection, requirements, the registry follows more than 28,401 cancer cases annually. Follow-up letters are sent to physicians and patients to ensure data is current and that accurate outcomes are reported.

Registry data is reported annually to the Commission on Cancer National Cancer Database. All data submitted to the National Cancer Database for the Annual Call for Data are thoroughly reviewed to guarantee that all submissions are error-free. Registry data also is reported regularly to the Kentucky Cancer Registry, which ensures inclusion with the Surveillance, Epidemiology, and End Result national cancer data.

The Commission on Cancer National Cancer Database quality reporting tools, the "Cancer Program Practice Profile Reports," are used by the Network Cancer Committee to monitor the quality of patient care at Norton Cancer Institute. The Network Cancer Registry diligently collects cancer treatment information to ensure completeness of data in the Cancer Program Practice Profile Reports. The online Cancer Program Practice Profile Reports are updated as additional treatment information is collected, and supplementary National Cancer Database submissions are performed as necessary to update the Cancer Program Practice Profile Reports.



In 2014, 25 administrative and clinician requests for network cancer data were received. Due to continued growth of the Network Cancer Registry, our team has grown as well. It is composed of 16 cancer data analysts, who coordinate abstracting, follow up and assist with other department projects, and three cancer data compliance specialists, who monitor quality and manage outcomes studies. A cancer survivorship analyst is responsible for the survivorship treatment care plans. Five registry coordinators are responsible for coordinating multi-facility tumor conferences. One department secretary assists with administrative duties.

The Norton Cancer Institute Network Cancer Registry brings the full resources of comprehensive cancer facilities, technology and services together to improve enhance education and broaden clinical research.

2014 statistical information

Top seven sites of new cancer cases Race distribution





Gender distribution



Cancer cases with Hispanic origin



No definit Chemo or Surgery/c Surgery/r Chemo/ra Surgery/c Chemo/ot Radiation Surgery/c Surgery/r Surgery/c other Surgery/ Other only Chemo/ra Radiation/ Five-year survival by stage (diagnosed 2010)

| Top five malignant sites | | | | | | | |
|--------------------------|--------|---------------|-------|-------------|----------|--|--|
| | Breast | Lung (NSC) | Colon | Endometrium | Prostate | | |
| Stage 0 | 99.1% | 50% | 77.8% | 100.0% | * | | |
| Stage I | 100% | 63.5% | 95.2% | 95% | 100% | | |
| Stage II | 93.6% | 66% | 88.4% | 100% | 100% | | |
| Stage III | 83.3% | 31.9% | 68.3% | 90% | 93.9% | | |
| Stage IV | 33.9% | 6.1% | 21.2% | 20% | 68.6% | | |
| Overall | 94.6% | 31.4% | 67.4% | 91.6% | 98.6% | | |

Top treatment composites

Surgery o

| nly | 1,123 | 30.75% |
|-----------------|-------|--------|
| ive Rx | 469 | 12.85% |
| ıly | 306 | 8.38% |
| hemo | 296 | 8.11% |
| adiation/other | 228 | 6.24% |
| adiation | 209 | 5.72% |
| ther | 201 | 5.5% |
| ther | 145 | 3.97% |
| only | 131 | 3.59% |
| hemo/radiation | 131 | 3.59% |
| adiation | 126 | 3.45% |
| hemo/radiation/ | 92 | 2.52% |
| hemo/other | 89 | 2.44% |
| у | 52 | 1.42% |
| adiation/other | 32 | .88% |
| /other | 20 | .55% |
| | | |





| CP3R for breast cancer: | Estimated performance rates | | | | | | |
|---|-----------------------------|------------------|------------------|----------------------|---------------------------|--------------------------------|--|
| 2013 diagnoses | NCI 2013 | Kentucky 2013 | My census region | My ACS** division | My CoC*** program type | All CoC-approved programs 2013 | |
| Breast conservation surgery rate for women with AJCC clinical stage 0, I or II breast cancer (surveillance) | 60.3% | 54.8% | 50.7% | 51.8% | 61.8% | 63% | |
| Image or palpation-guided needle biopsy (core or FNA) is performed to establish diagnosis of breast cancer. (quality improvement)* | 74.7% | 85.1% | 87.2% | 86.7% | 89.6% | 88.4% | |
| Radiation therapy is considered or administrated following any mastectomy within 1 year (365 days) of diagnosis of breast cancer for women with >= 4 positive regional lymph nodes. (surveillance)* | 78.1% | 80.5% | 82.7% | 82.8% | 84.4% | 83% | |
| Radiation therapy is administered within 1 year (365 days) of diagnosis for women under age 70 receiving breast conserving surgery for breast cancer. | 92.2% | 92.9% | 89.3% | 89% | 91% | 89.9% | |
| Combination chemotherapy is considered or administered within 4 months (120 days) of diagnosis for women under 70 with AJCC T1c N0 M0, or Stage II or III ERA and PRA negative breast cancer. | 90% | 92.9% | 91.8% | 91% | 91.3% | 91.1% | |
| Tamoxifen or third generation aromatase inhibitor is considered or administered within 1 year (365 days) of diagnosis for women with AJCC T1c NO MO, or Stage II or III ERA and/or PRA positive breast cancer. | 98.7% | 91.1% | 87.6% | 86.9% | 91.2% | 88.4% | |

*Not applicable **American Cancer Society ***Commission on Cancer

These are the 2013 performance rates for Norton Cancer Institute, comparison state rates and national performance rates for all Commission on Canceraccredited facilities.

As an approved Network Cancer Registry by the Commission on Cancer, Norton Cancer Institute is required to participate in Commission on Cancer quality studies. Included in these quality studies are Cancer Program Practice Profile Reports for breast, colon and rectal cancer cases. Cancer Program Practice Profile Reports was designed to use cancer registry data submitted to the Commission on Cancer through the National Cancer Database to "improve the quality of data across several disease sites, foster pre-emptive awareness to the importance of charting and coding accuracy and improve clinical management

and coordination of patient care in the multidisciplinary setting." (Cancer Program Practice Profile Reports [v3] - Overview Commission on Cancer, first released March 2014; last updated September 2015).

CP3

Adjuvant ch administere of diagnosis AJCC Stage cancer. ____ At least 12

removed an resected col

CP3

Radiation t administere of diagnosis with clinical or Stage III rectal cance

Data source: Cancer Patient Data Management System (repository for Norton Cancer Institute Network Cancer Registry data); National Cancer Database CP3R (V3) - Overview Commission Cancer, first released March 2014; last updated September 2015.

| | Estimated performance rates | | | | | | | |
|---|-----------------------------|------------------|---------------------|----------------------|------------------------------|---------------------------------------|--|--|
| 3R for colon cancer: 2013 diagnoses | NCI 2013 | Kentucky 2013 | My census region | My ACS** division | My CoC*** program type | All CoC- approved programs 2013 | | |
| chemotherapy is considered or red within 4 months (120 days) sis for patients under age 80 with ge III (lymph node positive) colon | 96.9% | 91.6% | 87.4% | 87.1% | 89.7% | 87% | | |
| regional lymph nodes are and pathologically examined for colon cancer. | 81.6% | 89.2% | 86.5% | 86.2% | 91% | 89.8% | | |

| R for rectum cancer: 2013 diagnoses | Estimated performance rates | | | | | | |
|---|-----------------------------|------------------|------------------|----------------------|------------------------------|---------------------------------------|--|
| | NCI 2013 | Kentucky 2013 | My census region | My ACS** division | My CoC*** program type | All CoC- approved programs 2013 | |
| therapy is considered or red within 6 months (180 days) sis for patients under age 80 of al or pathologic AJCC T4NOMO I receiving surgical resection for cer.* | 88.9% | 91.1% | 86.4% | 85.9% | 84.8% | 84.1% | |

*Not applicable **American Cancer Society ***Commission on Cancer







My hero is my fraternal twin, Debbie Gahan (Denise pictured on right)

Denise Valente Staying strong thanks to her twin

For years, Denise Valente suffered from a nonmalignant fibrocystic breast condition. Her breasts would get tender, swollen and lumpy, and she would have the cysts aspirated. It was so predictable, in the words of the 58-year-old Denise, "I got pretty nonchalant about it."

cancer was diagnosed.

"My cancer diagnosis was like a death sentence," Denise recalled. "My life seemed over, and I wondered how long I had left. I wondered what kind of battle I was facing."

Denise would take her chemo infusions at Norton Cancer Institute – Audubon, a stone's throw from where she has been employed for the past 28 years. She knew she was in the best possible hands.



"I've learned to go on and I don't feel like I'm going to die anymore," she said. "There's life after cancer."

Then in 2010, she discovered a lump in her right breast that in time grew to the size of a golf ball. She consulted with a surgeon friend at Norton Audubon Hospital, where she works. An aspiration procedure failed to remove the lump, but fluid was extracted and sent to the laboratory, where breast

The stark news followed: Her stage 2 breast cancer, though not found in her lymph nodes, was aggressive. Her treatment plan called for immediate surgery then six months of chemotherapy.

For her monthly chemo infusions, Denise knew she would need help daily to withstand the fatigue, nausea and other harsh side effects associated with her therapy regimen. She didn't have to look far. Providentially, Denise's fraternal twin, Debbie Gahan, had moved in with her a few weeks before the diagnosis. Both were single moms with no kids at home and decided to combine households.

"I was so exhausted that, at times, I couldn't lift myself out of bed," Denise said. "I was nauseous, had severe joint pain and lost 25 pounds. Debbie took me to every chemo infusion and doctor's appointment.

She was by my side in

the middle of the night ____ when my head was hanging over the toilet. She never complained," Denise said.

Denise, now a five-year cancer survivor, has learned a lot about the important things in life.

2014 quality studies

Timing and reasons for visits to the emergency department by patients in active cancer treatment

Structure/focus of problematic quality issue

For cancer patients seeking care for cancer-related or treatment-related complaints, a trip to the emergency department can be very taxing. It can expose them to disease. The wait can be stressful. There are additional costs to the patient. And the ED may not be equipped to handle cancer patients' symptoms or complaints. Thus, under certain circumstances, cancer patients' visits to the ED may reflect issues not adequately addressed or managed during routine care.

Criteria

The study analyzed 62 cases seen in the ED for cancer-related or treatment-related complaints. Parameters were:

- Demographics
- Disease characteristics
- Day of week and time of day of visit
- Symptom/complaint that prompted ED visit
- Service provided in the ED
- Timing of last encounter with Norton Cancer Institute and type of encounter

Findings

Cytotoxic chemotherapy, especially including taxanes, seems to be associated with more visits to the ED. The most frequent symptoms were pain, nausea, fatigue, constipation and vomiting.

The three main diagnoses were non-small cell lung cancer, breast cancer and colon cancer. Sixty-eight percent of visits occurred on weekdays. Sixty-two percent took place between 8 a.m. and 5 p.m. Fifty-eight percent had an encounter with Norton Cancer Institute within 48 hours of the visit to the ED. Half of those encounters had taken place on the same day as the visit to the ED.

Most patients received IV fluids, anti-emetics, analgesics, medication adjustments, imaging studies and lab exams.

Action plan

This was an observational study that will allow us to look for more specific details in future studies. The information strongly supports the notion that a dedicated symptom clinic would reduce the need for Norton Cancer Institute patients to visit the emergency department, as all services the patients received can be provided in an outpatient setting.

Structure/focus of problematic quality issue

For ovarian-type cancers (183.0 cancer of ovary, 183.2 fallopian tube cancer, 158.9 primary peritoneal cancer = ovarian type cancer), an increase in patients' complaints of chemotherapy-induced neuropathy (CIPN) has been noted. Better assessment and documentation of patients' CIPN symptoms are needed in order to intervene early in the initial cancer treatment period.

Criteria

Chart review of patients with ovarian-type cancer diagnosed between January 2011 and December 2013, age 19 and older, who received carboplatin/paclitaxel as initial chemotherapy. Parameters were:

Findings

Of those with documentation of CIPN, most (74 percent) did not affect cancer treatment. Chemotherapy was documented as discontinued or changed to a different chemotherapy in 14.8 percent of the charts, and chemotherapy dose was reduced in 3.7 percent of the charts. By the sixth cycle, of the patients who developed CIPN, symptoms were described as "stable" (48.1 percent), "less intense" (18.5 percent), "more intense" (3.7 percent) or "resolved" (14.8 percent). Fifteen percent of the charts had no documentation.

Action plan

Development of a practice-based assessment protocol for chemotherapy-induced peripheral neuropathy

- Where CIPN was documented in the patient's record
- Who documented CIPN (a physician or advanced practice provider?)
- How often CIPN was documented
- Which cycle of chemotherapy was CIPN first documented as present
- How CIPN was described

 Educate patients regarding CIPN. Create a standardized CIPN assessment tool to be used by all providers.





Lonnie Gardner In sickness and in health

The lump on Lonnie Gardner's left arm looked innocuous. Maybe an insect bite, he reasoned. For weeks in 2013, the human resources professional went about his business, unconcerned. But the lump got larger and caught the attention of his wife, Megan, who suggested he consult with a dermatologist. More weeks went by. She kept insisting. He kept putting it off. Finally, he made the appointment.

then age 31, was floored.

This early detection became a lifesaver since the normal age for a colonoscopy is between 45 and 50 years old. Lonnie will have to undergo a colonoscopy annually as a preventive measure.

"I'm very fortunate that the polyp was discovered early," he said.

For a time, Lonnie's cancer took a back seat to his colon condition. But after he recovered from surgery in November 2014, the father of two underwent radiation treatments for his lymphoma. He can happily say now he is cancer-free.

Lonnie gives all of the credit to his wife.

Lonnie Gardner My hero is my wife, Megan

The dermatologist biopsied the lump and sent the tissue to the laboratory, and the result came back as non-Hodgkin lymphoma, a blood cancer. Lonnie,

"I never dreamed I would get cancer," he said. "I was shocked and wondered if I was about to die. I didn't know where to go from there and was pretty anxious those first few days. But I had my family there to support me."

Once again, Megan stepped in, helping her husband find the best specialists.

"She said, 'We're going to go through this the right way and see the best of the best. Everything is going to be just fine," Lonnie said.

Lonnie went to see a Norton Cancer Institute oncologist, who ordered a PET scan that revealed his cancer had not spread. Good news there. But the imaging test picked up something else: A suspicious-looking spot in his colon. A gastroenterologist performed an endoscopy and colonoscopy, discovering a large precancerous polyp that required removal.

"Megan supported me and directed me to the right specialists," he said. **FF** Her insistence that I go see the dermatologist

saved my life, no doubt about it.



Pediatric cancer services

Hope and healing

Kosair Children's Hospital is a source of hope and healing for the 100-plus children diagnosed with cancer each year and the nearly 1,000 children annually who are in ongoing cancer treatments, clinics and follow-ups. The Addison Jo Blair Cancer Care Center at Kosair Children's Hospital is the oldest continuously accredited children's oncology program by the American College of Surgeons' Commission on Cancer, holding accreditation since 1959. Affiliated with the Children's Oncology Group and the National Cancer Institute, the Addison Jo Blair Cancer Care Center offers highly advanced cancer research and treatment options for children fighting all types of cancer at all stages.

As the teaching facility for the University of Louisville School of Medicine Department of Pediatrics and a Magnet-designated hospital recognized for nursing excellence, Kosair Children's Hospital maintains an unwavering dedication to the children of this community and region. Decades of pediatric expertise, comprehensive treatment and support services make Kosair Children's Hospital an excellent choice for the treatment of all forms of childhood, adolescent and young adulthood cancers.

The hospital's multidisciplinary approach to children's care integrates the efforts of many specialists in cancer, including oncologists, hematologists, cardiologists, nephrologists, infectious disease specialists, surgeons, nurses, social workers, chaplains and pharmacists. The hospital's oncology specialists also are faculty members of the U of L School of Medicine Department of Pediatrics. In addition to their aggressive treatment of cancer, they focus on preserving quality of life during and immediately after treatment, as well as long-term, to minimize late effects associated with treatment. This approach is patient- and family-centered, meaning it involves the entire family in the plan of care. When a child has cancer, it affects the whole family. The hospital's oncology program offers resources to address all aspects of a family's day-to-day life, including psychosocial support for patients, parents and siblings; areas for relaxing and sleeping; and familyoriented activities.

Treatment and services

The Addison Jo Blair Cancer Care Center provides inpatient and outpatient multidisciplinary evaluation and treatment of children with a wide range of cancers, including leukemia, Hodgkin and non-Hodgkin lymphoma, brain tumors and all types of childhood solid tumors. It also includes the state's only stem cell and bone marrow transplant program specifically for children and an eight-bed, HEPA-filtered stem cell transplant unit designed for stem cell/bone marrow transplant patients and other patients who may be immunocompromised.

Each child is different, and multiple treatment options are available to meet their special needs. These include chemotherapy for all types of pediatric cancers, high-dose chemotherapy with stem cell rescue, reduced-intensity stem cell transplants, autologous and allogeneic stem cell/bone marrow transplants, and supportive care.

The Addison Jo Blair Cancer Care Center also treats blood disorders, such as sickle cell anemia, hemophilia, idiopathic thrombocytopenic purpura, neutropenia and other types of anemias. The hospital has the region's only pediatric apheresis program offering many types of apheresis procedures, including photopheresis to treat blood disorders, rejection after solid organ transplantation, graft-versus-host disease that sometimes occurs after stem cell/bone marrow transplant, and auto-immune disorders such as Crohn's disease. The center also is among the first in the region to offer a red blood cell exchange program, which is virtually a painless treatment for sickle cell disease that helps to minimize complications such as acute chest syndrome.

To treat the special needs of children with various types of brain tumors, the Kosair Children's Hospital neuro-oncology program comprises a multidisciplinary team of pediatric oncologists, neurosurgeons, neurologists and radiologists who meet monthly to address the multiple issues/needs of this special group of young patients. The team is in ongoing contact with nationally recognized experts in the treatment of rare and complex neurologic cancers and neurological complications associated with cancer. Children with brain tumors also have access to multiple research and standard of care treatment protocols.

Child life services

A cancer diagnosis is a traumatic, life-changing event at any age. For children who don't understand what their diagnosis means, why they have to spend time in the hospital or why painful treatments are necessary, child life therapists are available to help families understand and manage stressful hospital experiences.

Expressive art therapists incorporate art, puppetry, writing and drama as therapeutic interventions to help children, parents and siblings express themselves and cope with their cancer experiences.

Music therapists address physical, psychological, cognitive and social functions through a variety of music-related activities. Benefits of music therapy include improved sleep and appetite, pain relief and increased relaxation.

Playrooms offer "safe" places where no medical procedures are allowed. Children can visit playrooms, or toys from playrooms can be taken to patients who are unable to leave their rooms. Teens have access to video games, computers, arts and crafts, age-appropriate magazines and books, as well as child life therapists, who encourage communication and understand teens' need for independence and privacy.

Other ancillary services include Jarrett's Joy Cart, which distributes toys, books and movies to patients in the Addison Jo Blair Cancer Care Center, and Caps for Kids, a program that makes available hats autographed by celebrities, entertainers and athletes to help young cancer patients cope with hair loss during treatment.

The nonprofit Flashes of Hope organization provides professional volunteer photographers who visit the hospital once a month to create uplifting portraits

The Family Link Cord Blood Storage Program is a service of Norton Healthcare of children fighting cancer. These portraits help children feel better about their changing appearance by celebrating it through photography. for storage of umbilical cord blood from newborns. A private facility started in 1998, Family Link serves families delivering within a four-hour driving distance Shield of Faith, a program composed of local police officers, brings a wagon of from Louisville. A baby's stem cells are preserved from the umbilical cord and toys and games to patients once a week to help keep their spirits lifted. placenta at birth. The cells are kept at ultra-low temperatures through a process To supplement the nutritional needs of patients' families, meals are provided called cryopreservation and stored in the Stem Cell Laboratory located at throughout the month by generous contributions from Camp Quality, Texas Kosair Children's Hospital for up to 20 years.

Roadhouse and other groups.

Family Link provides access to stored stem cells for transplants, one of the best The Coping Cart, a mobile multimedia center, gives patients at Kosair Children's methods of treatment for several types of leukemia as well as other cancers and Hospital the opportunity to create videos to share their strategies for coping diseases. Stem cell transplants can help the body rebuild blood cells destroyed with health or life issues. With families' permission these videos are posted on by disease or treatments such as chemotherapy. Norton Healthcare is the only CopingClub.com to help other children and families who may feel alone in their organization in the region offering a private cord blood storage program. experiences.

All child life services are funded by the Children's Hospital Foundation. For ways to help, visit HelpKosairChildrensHospital.com

Palliative care

The Hearts and Hands Palliative Care Team at Kosair Children's Hospital focuses on treating the pain, symptoms and stress faced by children and families during treatment for complex or life-threatening medical conditions. Palliative care is provided in conjunction with other treatments and helps the child remain comfortable during any stage of illness. The palliative care team promotes the best quality of life for hospitalized children and their families through education, advocacy, communication and palliative expertise.

The palliative care team is made up of a pediatrician, clinical nurse managers, a nurse clinician, social services and pastoral care specialists. They collaborate with child life specialists, expressive art therapists, psychologists, occupational therapists, physical therapists, nutritionists and care providers as needed.

Research and clinical trials

The Addison Jo Blair Cancer Care Center at Kosair Children's Hospital is affiliated with national organizations, including the Children's Oncology Group and the National Cancer Institute. Through the Children's Oncology Group, the most current Phase I, II and III clinical trials and treatment protocol options are accessible to our pediatric patients. These protocols provide the most effective treatment for children with cancer.

Family Link Cord Blood Storage Program

Innovative research

In addition to more than 100 clinical trials available through the Children's Oncology Group, a variety of new and innovative trials are being conducted at Kosair Children's Hospital under the leadership of Kenneth Lucas, M.D., chief of the Division of Pediatric Hematology/Oncology at Kosair Children's Hospital and professor of pediatrics for the University of Louisville School of Medicine Department of Pediatrics. These include:

- A Phase I/pilot II trial using vaccine therapy in patients with relapsed brain tumors and brain tumors that do not respond to standard therapy. With conventional chemotherapy, these children have a very to attack certain tumor cell markers has the potential to provide a viable treatment option for these patients.
- A Phase I study using vaccine immunotherapy in patients with relapsed metastatic solid tumors, such as neuroblastomas and sarcomas. This is another group of children with a very low survival rate with conventional chemotherapy.
- A Phase I trial evaluating the use of donor stem cells for patients with relapsed or therapy-resistant/refractory Ewing's sarcoma. The study attempts to minimize toxicity of the stem cell transplant by using a conditioning treatment before transplantation with the goal of achieving long-term survival for these patients.
- A trial using a novel conditioning treatment in preparation for stem cell or bone marrow transplantation in children with severe congenital anemias, such as sickle cell disease, thalassemia and Diamond Blackfan





Carroll Grossman A surprise companion on the running course

Carroll Grossman, a 71-year-old distance runner, felt in the best shape of her life when she found a lump in her left breast and was diagnosed with stage 2 breast cancer. At first, she denied it.

too."

True to his word, Dr. Spalding met Carroll on the steep 6-mile course. Carroll told Dr. Spalding that if she lagged behind, he should go on ahead and double-back for her so they could finish together.

Carroll recalled him saying, "No, I'll just run with you however fast you're going. And if you have any trouble getting up the hills,

I'll carry you up. That was in February, and Carroll has since kept her cancer at bay while staying active as a runner, eating a well-balanced diet and writing in her journal to cope with her disease.

"My three R's are reading, writing and running," she said.

impressed her the most.

"Dr. Spalding stands out as a shooting star, a comet that leads the way," she said. "He brought me along at a critical time and really encouraged me to be who I am."

"I have always been about good health and couldn't believe this was happening to me," she said. "After the biopsy came back positive in the fall of 2014, I got into my car for the trip home shaking. I called my husband to help me calm down."

A lumpectomy was performed. Afterward, Carroll pressed her surgeon about when she could lace up her running shoes. In three weeks, she hit the trails of Cherokee Park near her home, once again in her element, her spirits restored.

After the holidays, she began to fret again. Radiation was scheduled and she worried it would derail her running regimen. "Lovin' the Hills," a 50k trail run in Jefferson Memorial Forest (with 6- and 15-mile options), was coming up and she was determined to take part. Her son Eric, a nationally prominent runner, had founded the race. This was a command performance.

She asked her radiation oncologist, Aaron Spalding, M.D., Ph.D., if she could participate in the race. "Yes," he emphatically replied, "and I'll be there,

During her darkest hours, what has sustained Carroll is running and writing friends and family (especially her sweet grandchildren!), as well as the support from friends from church and the University of Louisville. But it is one radiation oncologist's big heart, kindness and moral support that have

Kosair Children's Hospital Cancer Registry

The Norton Cancer Institute Network Cancer Registry also manages the Kosair Children's Hospital Cancer Registry. In 2014, 73 new cancer cases were entered into the Kosair Children's Hospital Cancer Registry has collected data on 1,479 cancer cases. Beginning in 2004, the registry began collecting data on benign/borderline brain and central nervous system tumors as required by law.

In addition to entering information on new cancer diagnoses, the Kosair Children's Hospital Cancer Registry also follows all pediatric cancer and benign/borderline brain and central nervous system tumor patients until they reach age 27. Currently, the registry follows 1,062 pediatric patients, maintaining a five-year follow-up rate of 90 percent and a reference date (1995) follow-up rate of 80 percent.

2014 statistical information









| Five-year survival rates for top five cancer sites | | | | | | |
|--|-------------------------------|-------|--|--|--|--|
| | Kosair Children's Hospital | ICCC* | | | | |
| Lymphocytic leukemia | 86.5% | 82.8% | | | | |
| Connective and soft tissue | 65.4% | 71.8% | | | | |
| Brain | 77.6% | 73.1% | | | | |
| Thyroid | 100% | 99.5% | | | | |
| Bone | 72% | 71.8% | | | | |

Caucasian African American Other

*International Classification of Childhood Cancer (2005 to 2011), part of the SEER Cancer Statistics Review 1975-2011, National Cancer Institute

Gender distribution

52

Top treatment composites







Micheal White Grateful for second chances

In May 2015, Micheal White, severely short of breath, rushed to the emergency room at Norton Brownsboro Hospital. Chest X-rays revealed fluid in his lungs. He was hospitalized overnight so doctors could monitor him and run more tests.

yesterday.

"We prayed and I turned it over to God," the 51-year-old businessman and philanthropist said. "We have to look for the blessings in the adversity that God allows us to have. It's how we react to that adversity that really counts."

Micheal started several businesses in the West End of Louisville, where he grew up, and hired recovering alcoholics and addicts to work for him. He also co-founded halfway houses for sober living in the West End where, he said, there is a scourge of widespread crime and addiction.

mentors.

He also is grateful to the physicians and staff of Norton Cancer Institute – Brownsboro, where he received five rounds of chemotherapy. To mark his final treatment in September, Micheal asked Mayor Greg Fischer to sign a proclamation honoring "Mike's Angels" — the name he gave Norton Cancer Institute staff who cared for him during his treatments. His friend, former University of Kentucky basketball star Derek Anderson, stopped by for the recognition ceremony. Also in attendance was Micheal's wife, Latanya.

"Latanya has been very patient and understanding," he said. "She's a wonderful woman and is my amazing angel."

Micheal said adversity has taught him to be more tolerant and patient, and that addicts and alcoholics, like cancer patients, deserve empathy, compassion and support.

"We should have a more level playing field," he said.

Micheal White My hero is my wife, Latanya The next day, Micheal got the earth-shattering news: He had stage 4 lung cancer. A chaplain came to his room. Micheal remembers the scene like it was

Micheal speaks from experience. In his 20s, he was a drug addict and alcoholic. At one time, he was seven years behind in his child support. Twenty years ago, he hit rock bottom with the help of a crack pipe and a can of beer.

"I wanted to die," he said. But something in him refused to give up. He asked God to help him to get sober and become a responsible, caring father to his three daughters. And he succeeded!

Grateful for his own second chances, Micheal also is a 15-year member of the 100 Black Men of Louisville, where he works with youth in need of

2014 quality studies

Adherence to central line-associated bloodstream infection maintenance bundle

Structure/focus of problematic quality issue

The central line-associated bloodstream infection (CLABSI) rate in the Kosair Children's Hospital hematology/oncology unit was noted to be above the national benchmark in 2013. A review of our processes identified an opportunity around standardization of central line care. The initial baseline data suggested adherence to the CLABSI maintenance bundle was below 70 percent. Our incremental goal for bundle compliance was set at 76 percent, and we have gradually increased over time to greater than or equal to 90 percent compliance.

Criteria

All central lines in hematology/oncology patients admitted as inpatients were monitored for adherence to CLABSI bundle components. Bundle components included documentation of continued need, documentation and observation of "scrub the hub" for 15 seconds, caps dated/timed, and dressings clean, dry and intact.

Findings

Documentation of continued need was a nursing responsibility and initially was the most missed item of the bundle. Challenges were identified during observations of scrubbing the hub for 15 seconds (hospitalwide) and maintaining dry, occlusive dressings.

Action plan

A team consisting of hematology/oncology unit leadership, hospital epidemiologists and infection preventionists developed and implemented a method to observe, track and collect reliable CLABSI maintenance bundle compliance data for inpatients. As challenging portions of the bundle were identified, strategies were put in place to assist with compliance. Physicians were made responsible for daily review and recording of documentation of continued need. Alcohol caps on all ports were trialed, then implemented, and are now used in lieu of the 15-second scrub of the hub. A new central line dressing product also was trialed and implemented.

CLABSI maintenance bundle compliance continues to be monitored, and any opportunities that arise are promptly addressed. The data is shared at Kosair Children's Hospital CLABSI Team meetings.

Result improvement

The Kosair Children's Hospital hematology/oncology unit CLABSI maintenance bundle was consistently over the set goal for quarters two through four of 2014. We were at 90 percent (benchmark) and above for guarters three and four 2014. The number of CLABSIs on the unit decreased from 22 in 2013 to 10 in 2014.

Criteria

Findings

Barriers were identified:

Action plan

Standardized education with all health care providers was reinforced and mechanisms were implemented to ensure adequate hand gel was available in all areas of the hospital. Environmental services, patient care associates and administrative associates were assigned responsibility for ensuring dispensers were full and working as part of their daily routine. Stickers were placed on all mounted dispensers containing a phone number for staff to call when a dispenser was found empty or the battery needed to be replaced.

Monitoring of hand hygiene compliance continues. Performance is connected to overall hospital goals for 2015.

Result improvement

The hospital started guarter one 2014 with a cumulative hand hygiene compliance percentage of 71.6. This indicator met goal the remaining three guarters of 2014, with a cumulative total of 82 percent for the year.

Hand hygiene compliance

Structure/focus of problematic quality issue

Kosair Children's Hospital was part of a systemwide initiative to improve compliance with the "5 Moments of Hand Hygiene" and standardize a method for obtaining hand hygiene compliance data. Early data suggested our adherence was 70 percent or lower.

All health care professionals were monitored by an observer not associated with the unit. A minimum of 30 observations were required monthly. Trained observers intervened if a hand hygiene opportunity was about to be missed.

- Uncertainty about what the "5 Moments of Hand Hygiene" meant
- Working hand gel/slap dispensers were not always readily available
- There was not always a clear understanding of what designated the "patient zone"







Addie Roberts Backed by an army of 10,000

Addie Roberts is an extraordinarily courageous 4-year-old who has battled leukemia for half of her life. Since her diagnosis in September 2013, she has received countless rounds of chemotherapy, yet never complained.

preschool.

Her brave smile has touched thousands of people. A group of dedicated supporters, called "Addie's Army," help with encouraging words and support for the Roberts family of Hodgenville, Kentucky. The Addie's Army Facebook fan page numbers more than 10,000.

medical bills.

"The diagnosis literally knocked the breath out of us," Angela said.

The staff and physicians at Kosair Children's Hospital and Norton Cancer Institute have surrounded this exceptional little girl with loving care and the best possible treatment protocols. Her chemotherapy ended in December 2015, and Addie's parents are hopeful her leukemia will stay in remission.

"We feel extremely blessed with all the support that we have received," Angela said.

Addie can't be held down.

"I've never seen so much strength in a child," Angela said.

Ben and Angela Roberts Our hero is our daughter, Addie

Ben added: "After her treatments, she's ready to put it behind her, thinking, 'Where can I find my next rainbow?'"

Through it all, she's remained a typical child. She loves to drive her Power Wheels Jeep around the yard, pick pumpkins with her family and take her caterpillar, "Kirby," on walks through the neighborhood. Three hours after one of her 17 spinal taps, she was asking to go to soccer practice at her

"She is so precious. Praying for Addie," wrote one fan. Another said: "She's an amazing little girl and beautiful on top of it."

One post shows Addie wearing a T-shirt with the words "Strength is a child fighting cancer with a smile on their face."

Country music stars Gary Allan and Craig Morgan have donated their time and talent for fundraisers in Louisville to help the family pay mounting

Addie's parents, Ben and Angela Roberts, vividly recall the day Addie, their eldest daughter, developed a fever of 105 and a rash on her arm. Their pediatrician ran tests that revealed a dangerously low blood count and then made immediate arrangements to have Addie seen at Kosair Children's Hospital, where further testing determined she had leukemia.

"No matter what she goes through, she has a **big smile** on her face and **a positive attitude**."

Staff and locations

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Co-chairs

Lee Garlove Edie Nixon

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