

ANNUAL REPORT



2014



*Clinical trial participant and cancer survivor Patty Currey with husband Joe - Hays, KS
Patty's story is on page 7*

A MESSAGE FROM THE MEDICAL DIRECTOR

The Art of Collaboration was the theme of the 2014 Midwest Cancer Alliance annual meeting. It proved to be a prophetic choice for us this year.

Over the past year, the MCA has continued to build alliances with hospitals and medical professionals in the Midwest. Our membership has grown to include two new clinical research partners: North Kansas City Hospital and Olathe Medical Center. In addition, the list of cancer trials available to our clinical research partners continues to expand, and we are now working closely with some of those partners to help promote awareness of clinical trials and increase accruals through joint marketing and public relations campaigns.

Artful collaboration has been key to the education and outreach work we do, as well. The MCA's educational opportunities reach more medical professionals each year and the outreach programs and services the MCA offers our members have grown significantly. In addition to screenings, Turning Point, Kitchen Therapy and Pool Cool programs, the MCA now provides members with psycho-social oncology services like Going Forward and a free smoking cessation program. These programs are particularly critical in light of the growing numbers of cancer survivors and the devastating impact that tobacco has on the health of patients in Kansas and Missouri.

After four years of research, meetings and close collaboration with Children's Mercy, The University of Kansas Cancer Center, University of Kansas Medical Center and The University of Kansas Physicians, a unique clinic has opened that serves adult survivors of childhood cancer. The University of Kansas Cancer Center Survivorship Transition Clinic is one of a handful of clinics across the country to address the long-term care of pediatric cancer survivors in an adult setting.

The MCA has also been working closely with Truman Medical Centers on the development of its biobank. The biobank's collection of data and tissue samples will help researchers, near and far, find ways to prevent and cure cancer.

Like the creation of a work of art, collaboration isn't always easy. But with partnerships that advance research and treatment, it is well worth it.

Gary C. Doolittle, M.D.
Medical Director
Midwest Cancer Alliance



PARTNERS ADVISORY BOARD

The Midwest Cancer Alliance Partners Advisory Board (PAB) demonstrates the collaboration of key hospitals and research institutions in our region. These collaborations support The University of Kansas Cancer Center's National Cancer Institute (NCI) designation, leverages regional strengths such as drug discovery and development; and advances cancer prevention, early detection, treatment, and survivorship.

Purpose

To demonstrate research and education collaboration amongst key hospitals and research institutions for the benefit of the region and in support of The University of Kansas Cancer Center's NCI designation and efforts to obtain Comprehensive Cancer Center designation.

Functions

- Serve as advisors to the Director of The University of Kansas Cancer Center for the National Cancer Institute (NCI) designation process
- Ensure a shared vision for cancer research and education in the region
- Assist with the pursuit and maintenance of NCI designation by demonstrating cancer research and education collaboration among hospitals and research institutions in the region
- Participate in the strategic planning process of NCI comprehensive designation
- Make a significant annual financial commitment to support NCI comprehensive designation by building clinical research infrastructure at the respective sites to further collaboration



*Partners Advisory Board Chair
Robba Moran*

Governance

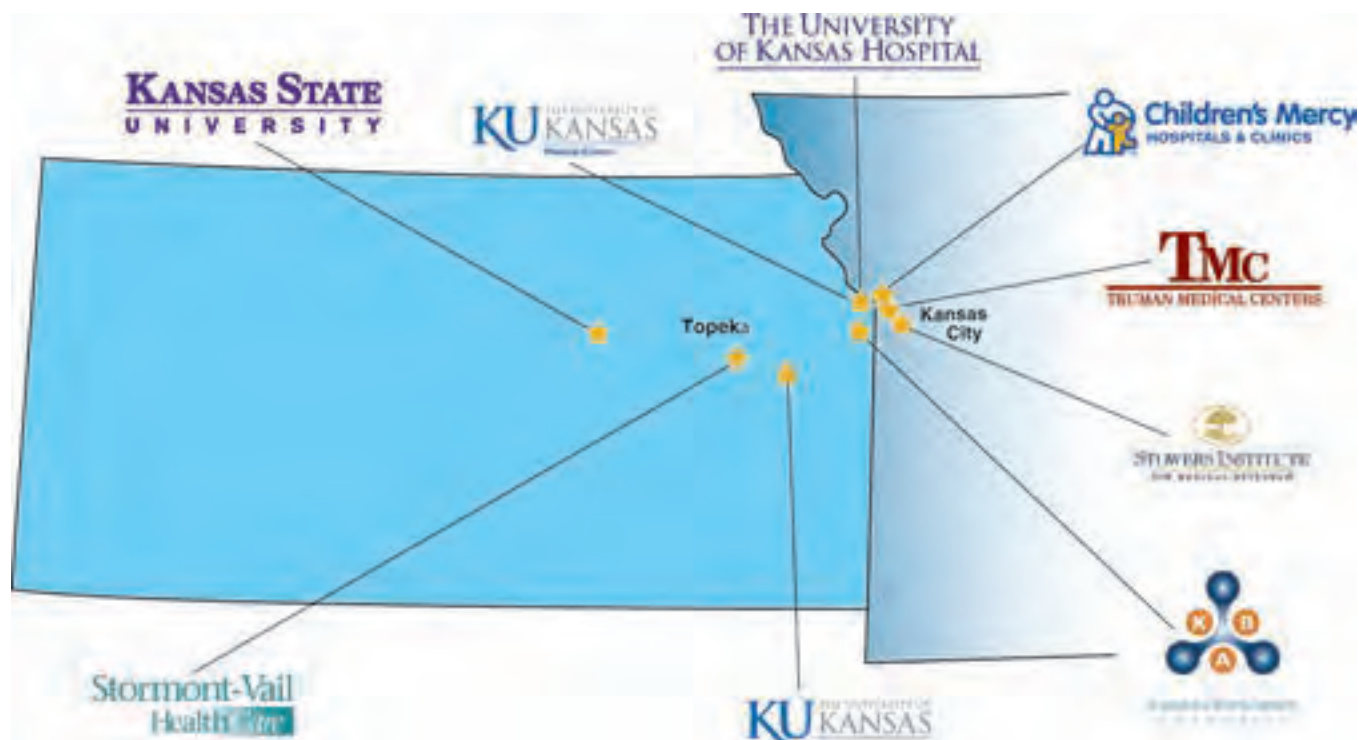
The MCA Partners Advisory Board serves in an advisory capacity to the Director of The University of Kansas Cancer Center and the Chief Executive Officer of the Midwest Cancer Alliance. The Chief Executive Officer of each PAB health care and research institution serves as a member of the PAB. The board is chaired by Robba Moran, a member of the Kansas Board of Regents. Each member serves as an equal partner with rights and responsibilities regarding research, education, philanthropy and community benefit.

Research

The commitment of the PAB members for collaborative research in the region has been demonstrated through innovative, robust partnerships. These cross-institutional relationships were made possible through organizational leadership and significant scientific cooperation. Since 2008, PAB members have committed over three million dollars to support collaborative, scientifically innovative research. The breadth and depth of this research represents the strengths and the priorities of the PAB organizations. Some examples include:

- **Children's Mercy Hospital** research projects have concentrated on cancer immunotherapy, drug development and the transition of pediatric cancer survivors to adult care. Read more about The University of Kansas Cancer Center Survivorship Transition Clinic on pages 10-11.
- **Stormont-Vail HealthCare** has focused on health service and dissemination research. They have implemented an alert within the electronic health record to notify health providers of potential clinical trials, assessed integrating palliative care in an outpatient cancer center, and are evaluating a community obesity prevention program for survivors of breast cancer. Read more about the clinical trial alert project on page 5.
- **Truman Medical Centers** is dedicated to supporting health equity research. Recent projects include building a biobank that will support researchers across the nation, assessing a nutrition literacy tool, evaluating attitudes and awareness of genetic research, and smoking cessation. Read more about the biobank on page 12.

2014 PARTNERS ADVISORY BOARD INSTITUTIONS



STORMONT-VAIL CANCER CENTER CREATES CLINICAL TRIAL ALERT SYSTEM TO IMPROVE ACCRUALS

Despite the critical role clinical trial participation plays in improving cancer care, less than five percent of adults with cancer take part in studies. Barriers include eligibility criteria restrictions, an incongruent relationship between cancer research programs and the cancer patient population, and a lack of systems that support a streamlined method for enrolling patients onto trials.

As part of a Partners Advisory Board initiative to improve accruals, Stormont-Vail concluded that it could streamline enrollments if physicians had an efficient means of being notified of potentially eligible trial patients. Focusing on a system-based approach, Stormont-Vail determined that clinical trial alerts (CTA) within the electronic health record would provide the tools that providers needed at the time that care decisions are made for patients. With PAB funding, the health care team worked with researchers to identify when the CTAs should trigger, key phrases for the alerts, and the importance of linking the alert to ClinicalTrials.gov. The clinical trials alerts have been live since May 2014. Providers now have additional tools at Stormont-Vail to identify potential treatment trials for their patients.

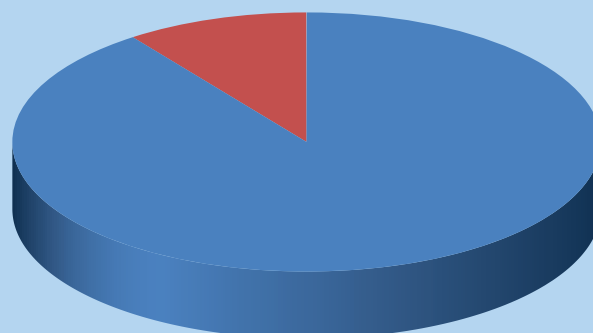
CLINICAL TRIALS



2010-2014 ACCRUAL

A total of 1,066 individuals enrolled on clinical trials supported by MCA Members.

- 959 Population Health Study Participants
- 107 Cancer Treatment Trial Participants



MCA MEMBER IN HAYS IS SITE OF A KEY BREAST CANCER TRIAL

During her fellowship at the University of Kansas Medical Center, Anne O'Dea, M.D., was offered the chance to help develop a cancer trial that would one day change lives across Kansas - and perhaps even further away than that.

In 2008, Qamar Khan, M.D., an associate professor of hematology/oncology at KU Medical Center, asked O'Dea to help write the protocol for a study that combined two cancer drugs, Abraxane and Herceptin. "Dr. Khan shared his idea for this protocol and the more I read about the topic, the more excited I was about the opportunity to be involved," says O'Dea.

The protocol was completed and approved in 2009, and the trial got underway before the end of the year. In 2010, O'Dea was offered a position in the oncology department at Hays Medical Center. This was also the year that Hays Medical Center (HMC) began offering Midwest Cancer Alliance (MCA) supported clinical trials.

"Hays Medical Center was interested in aligning itself with institutions that could help provide the most current treatments available," explains Chief Medical Officer Larry Watts, M.D.

Thanks to the staff and resources at HMC's Dreiling/Schmidt Cancer Institute and its location in rural Kansas, the hospital had the components needed to put the MCA mission into action -- improving access to the latest trials and treatments.

HMC began to explore clinical trial options soon after becoming a member of the MCA. "With O'Dea on staff at the hospital and her involvement in the Abraxane/Herceptin protocol, the study she helped develop seemed like a perfect place to start," says Watts. Once the trial was in place, staff at the Dreiling/Schmidt Cancer Institute began the process of screening cancer patients for eligibility. Study participants had to be women, at least 18 years of age, with Stage II or Stage III adenocarcinoma of the breast, an operable tumor, and several other criteria.

In June of 2012, Patty Currey, a recently retired speech and language pathologist and 35-year resident of Hays, was diagnosed with Stage III invasive ductal carcinoma. Her primary care physician referred her to O'Dea. Currey, O'Dea and Jo Klaus, the research nurse at HMC, discussed treatment options available, including the Abraxane/Herceptin trial available through the MCA.

"I committed to the trial because I wanted to do something that might help me and, possibly, a lot of other people, too," explains Currey.

By fall, Currey was undergoing weekly chemotherapy that included the medications approved for the Abraxane/Herceptin clinical trial. Fortunately, because of Hays' membership in the MCA, Currey only had to drive three miles for treatment, not the 256 miles to Kansas City. "Cancer is stressful enough," says Currey. "It was a relief to be able to get great care and treatment right in my own community."

Currey completed her chemotherapy in January 2013 and tests indicated the tumor had shrunk to the point where no cancer cells were identified. Currey's lumpectomy took place at HMC that winter and she completed radiation treatment in the spring. According to O'Dea, Currey's prognosis looks excellent.

While Currey's treatment has ended, clinical trials continue at HMC. "We're trying to get more patients like Patty involved in these trials," says O'Dea. "Every day there is more research, and there are more options. We're going to keep looking for the best ways to help patients in Hays."



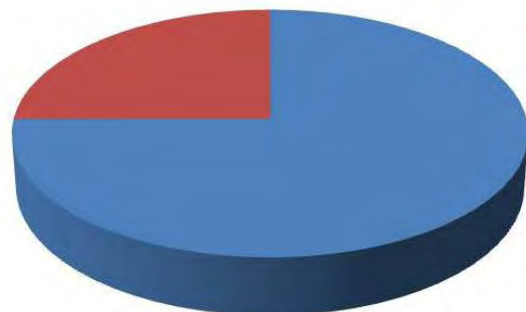
Cancer Survivor Patty Currey

COMMUNITY OUTREACH



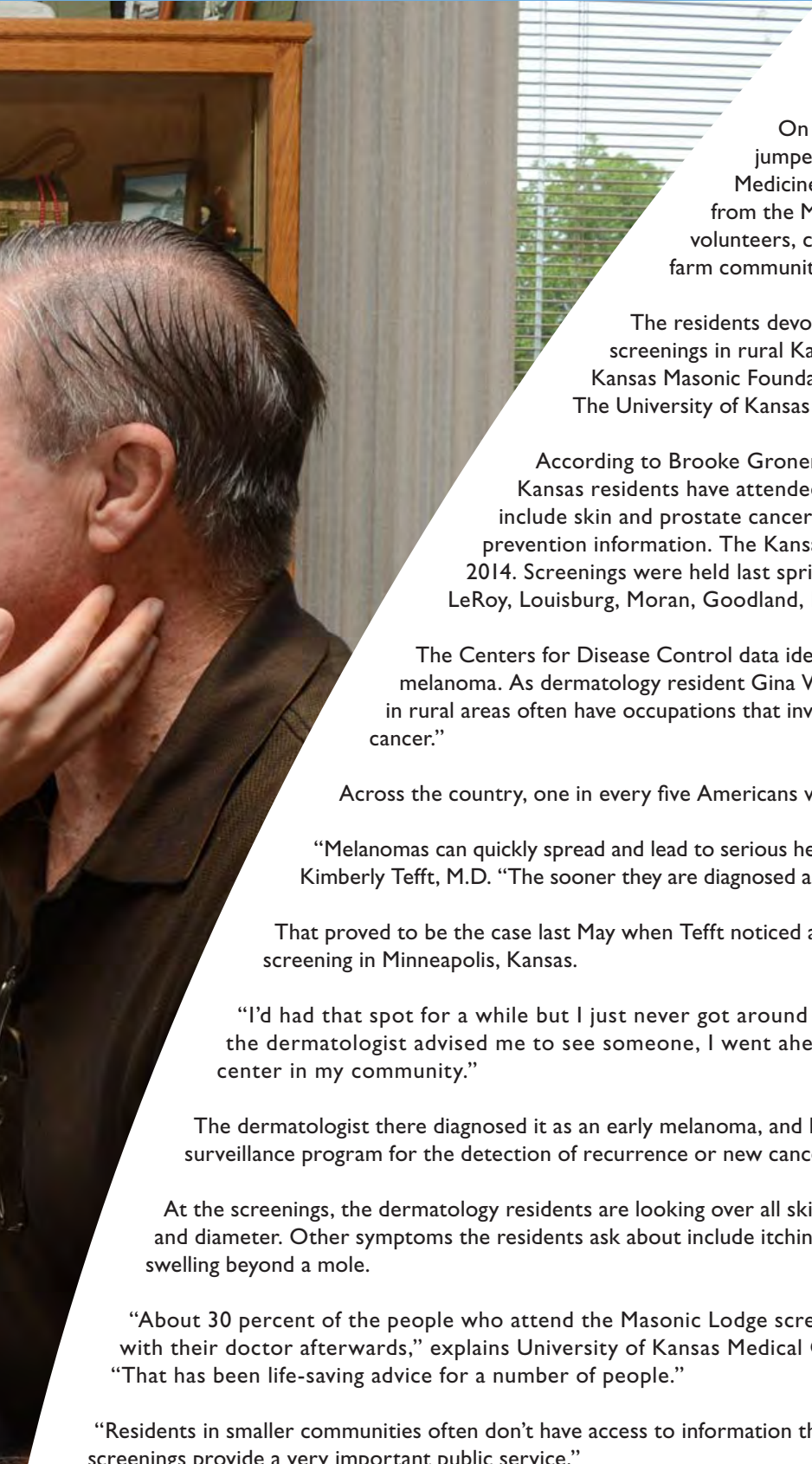
NUMBERS
SCREENED
2008-2014

Over 16,000 screened



■ 12,000 +
Normal
screening

■ 4,000 +
Follow-up
advised



KU RESIDENTS CONDUCT CANCER SCREENINGS IN RURAL KANSAS

On August 30, 2014 the population of Walnut, Kansas, jumped to 230. That's when University of Kansas School of Medicine urology and dermatology residents, along with staff from the Midwest Cancer Alliance (MCA) and area Masonic Lodge volunteers, came to town to provide a free cancer screening for the farm community that's nestled between Fort Scott and Pittsburg.

The residents devote several weekends every year to help with cancer screenings in rural Kansas communities. The screenings are hosted by the Kansas Masonic Foundation and coordinated by the MCA, the outreach arm of The University of Kansas Cancer Center.

According to Brooke Groneman, outreach director for the MCA, more than 3,000 Kansas residents have attended the Masonic screenings since 2003. The events include skin and prostate cancer screenings as well as bone density tests and cancer prevention information. The Kansas Masonic Foundation scheduled 11 screenings for 2014. Screenings were held last spring in Parsons and Pomona, Independence, Walnut, LeRoy, Louisburg, Moran, Goodland, Pittsburg and Girard.

The Centers for Disease Control data identifies Kansas as one of the states with higher rates of melanoma. As dermatology resident Gina Weir, M.D., points out, "It makes sense because people in rural areas often have occupations that involve chronic sun exposure which can lead to skin cancer."

Across the country, one in every five Americans will develop skin cancer over the course of their lifetime.

"Melanomas can quickly spread and lead to serious health problems and even death," says dermatologist Kimberly Tefft, M.D. "The sooner they are diagnosed and treated, the better chance a patient has for a cure"

That proved to be the case last May when Tefft noticed a dark spot on Jim Kay, a Masonic volunteer at a screening in Minneapolis, Kansas.

"I'd had that spot for a while but I just never got around to getting it checked," explains Kay. "However, once the dermatologist advised me to see someone, I went ahead and scheduled an appointment with a cancer center in my community."

The dermatologist there diagnosed it as an early melanoma, and Kay had it removed a short time later. Kay is now on a surveillance program for the detection of recurrence or new cancer.

At the screenings, the dermatology residents are looking over all skin areas for the ABCD's — asymmetry, border, color and diameter. Other symptoms the residents ask about include itching, tenderness, bleeding, scaly appearance and redness or swelling beyond a mole.

"About 30 percent of the people who attend the Masonic Lodge screenings are advised by the medical staff to follow up with their doctor afterwards," explains University of Kansas Medical Center associate professor, Anand Rajpara, M.D. "That has been life-saving advice for a number of people."

"Residents in smaller communities often don't have access to information that's easily available in larger towns," says Tefft. "These screenings provide a very important public service."

SURVIVORSHIP PROGRAMS



THE UNIVERSITY OF KANSAS CANCER CENTER SURVIVORSHIP TRANSITION CLINIC: CANCER SURVIVORSHIP WITH A SIDE OF BBQ

Becky Lowry, M.D., was up before the sun to serve burnt ends to hundreds of bicyclists on Sept. 27. Her early morning barbecue enthusiasm went beyond the fact that she lives in a town that takes its 'cue seriously. Lowry, an assistant professor of internal medicine at the University of Kansas Medical Center and medical director of The University of Kansas Cancer Center Survivorship Transition Clinic, volunteered at one of the stops on this year's Tour de BBQ.

The Tour de BBQ is an annual bike tour event during which barbecue samples are shared with participants as cyclists pedal their way past some of Kansas City's best known smoke shacks. Proceeds from the event in 2014 benefited The University of Kansas Cancer Center Survivorship Transition Clinic for adult survivors of pediatric cancer.



“If serving early morning BBQ helps give survivors of childhood cancer access to care tailored to their unique needs then I’m glad to be part of the effort,” Lowry says with a smile.

According to Tour de BBQ volunteer Chris Deffenbaugh, 700 cyclists participated in last year’s ride and he anticipates more than 1,000 will register for this year’s event. In 2013 the Tour de BBQ raised enough funds to underwrite the salary of Kyla Alsman, RN, the new Survivorship Transition Clinic nurse navigator. Alsman, who has nine years of experience as a pediatric oncology nurse at Children’s Mercy, helps young adult cancer survivors at medical facilities in the region transition to adult care at KU Medical Center.

CHILDREN’S MERCY HOSPITAL PARTNERS IN CLINIC LAUNCH

The Survivorship Transition Clinic was developed by the Midwest Cancer Alliance (MCA), the outreach arm of The University of Kansas Cancer Center, in partnership with Children’s Mercy, to address long-term health issues in adult survivors of childhood cancer. It is a companion program to the Survive & Thrive program at Children’s Mercy.

According to the National Cancer Institute, more than 80 percent of children live at least five years after a cancer diagnosis. Health authorities estimate that there are currently close to 400,000 individuals in the United States who have survived childhood cancer and the number keeps growing. But Alsman points out that those survivors are at high risk of secondary cancers, fertility issues, cardiovascular disease and endocrine problems.

As Joy Fulbright, M.D., medical director of Survive & Thrive explains, “One of the most difficult things for these survivors and their families is to transition from pediatric to adult care. When we discuss the new Survivorship Transition Clinic with families you can just see anxieties over making that change in care dissipate.”

That was the case for Morgan Simpson, a six-year survivor of non-Hodgkin lymphoma and Grand Marshal for this year’s Tour de BBQ. Simpson, now a certified nursing assistant in the oncology unit at St. Joseph Medical Center, received her initial treatment at Children’s Mercy but will soon switch her care to the Survivorship Transition Clinic.

“I was in high school when I was diagnosed but, now that I’m 21, I know it’s time to start getting my care in a place that is familiar with my history but offers adult health care services,” says Simpson. “It’s such a relief to have a clinic that helps me make the switch.”

Simpson is now followed by the Survivorship Transition team, which keeps track of her adult health care records and monitors her long-term risk issues during yearly follow-up visits. Simpson will receive educational materials and any necessary referrals from Alsman and Lowry during those appointments.

Alsman reports that word is spreading and they are hearing from patients from as far away as Florida. The clinic will soon offer counseling services and is exploring a nutrition program. Alsman anticipates other program enhancements in the future. “Our goal is to eventually make this transitional service available through telemedicine so that pediatric cancer survivors anywhere can receive the support we provide while being seen by their local physicians.”

“Tour de BBQ’s support has been instrumental to the clinic’s existence,” says Alsman. She adds with a laugh, “After helping out at the event I went home with BBQ stains on my clothes but it’s a small price to pay to thank all the riders who make it possible.”

For Simpson, serving as Grand Marshal in the Tour de BBQ is also about giving back. She says, “Participating in an event like this helps to let others who have gone through some of the same challenges know that there are resources to help them get through it.”

OTHER MEMBER SERVICES

PATIENT NAVIGATION

Patient navigators are health care professionals who help connect cancer patients and their families with the resources needed to address the educational, emotional, and financial needs that come with a diagnosis.

It is a strategy which eliminates barriers for people who don't have the knowledge or the resources to move rapidly through the healthcare system to earlier diagnosis and full treatment. Navigators work to erase structural barriers to care and enhance knowledge by coaching patients and families.

The Patient Navigator initiative was created and is sustained with the generous support of the Kansas Masonic Foundation. It is operated through the Midwest Cancer Alliance (MCA), the outreach division of The University of Kansas Cancer Center. One of the Alliance's goals is to facilitate advanced treatment for cancer patients as close to their homes as possible.

The MCA supports navigation professionals who help guide patients through the healthcare system to get the care they need. The MCA's Navigator works to develop and enhance access to patient navigator resources and support the MCA partners statewide as they develop their community-specific systems.

In this model, the MCA Navigator serves members of the network and community at large -- not just patients seen by a singular practice -- to enhance connections with multiple resources and create partnerships within the region and nation.

PSYCHOSOCIAL ONCOLOGY SERVICES

The MCA's Behavioral Health Therapist, Dr. Susan Krigel, helps members support the psychological well-being of cancer patients from the first day of diagnosis through survivorship. Our therapist is available to support and collaborate with members' existing psychological services and can offer guidance for members who wish to revitalize existing programs or initiate psychosocial oncology services. Individual and group counseling sessions are available through interactive televideo (ITV). The therapist is also available to travel to member sites for meetings and presentations.

Presentation topics for patients and health care providers include:

- Coping With Anxiety, Depression & Fatigue
- "Chemobrain"
- Cancer Survivorship
- Going Forward: Life After Cancer
- Anxiety, Depression & Suicide Among Cancer Patients
- Motivational Interviewing

MARKETING AND PUBLIC RELATIONS

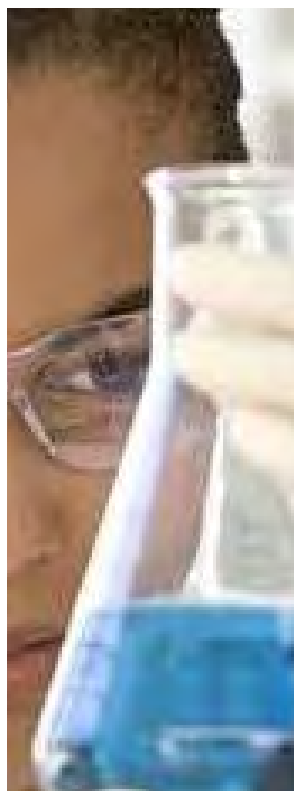
The MCA assists with marketing and public relations initiatives that help promote the member's participation in local cancer research, outreach and/or treatment programs. Services include bi-monthly networking calls for communications professionals, Website spotlights, social media support as well as collaborative assistance with press releases and collateral materials like brochures, flyers, banners and ads.

BIOBANK PARTNERSHIP WITH TRUMAN MEDICAL CENTERS

As research and technology advance at a rapid pace, the tools we use to support these developments must also progress. Biobanks -- a collection of specimens gathered for the purpose of research -- are one of our most critical means of making new discoveries.

The MCA has been working with Dr. Andrew Godwin, deputy director of The University of Kansas Cancer Center and director of the biorepository, to create a regionally supported biobank where participating members contribute specimens from their patients. A regional biobank increases the numbers and types of specimens available for local research and enhances KU Cancer Center's candidacy for the National Cancer Institute's (NCI) comprehensive cancer center designation.

In late 2014, Truman Medical Centers (TMC) developed the first of these regional biobanks in collaboration with the MCA and KU Cancer Center. Located in TMC's cancer center, the new biobank's skilled team of surgeons and researchers are already sending hundreds of samples to the biospecimen repository at KU Cancer Center.



CONTINUING EDUCATION

The MCA is committed to bringing the latest information on cancer research and care to its members. Various events are available in person or via the MCA's televideo (ITV) service.

Grand Rounds: Oncology Grand Rounds range from 1 to 1.5 hours in length and feature The University of Kansas Cancer Center faculty and nationally-renowned speakers presenting on a variety of cancer topics. The Continuing Education Office at the KU Medical Center administers and accredits the grand round sessions. All sessions are open to community health professionals; some are being made more widely available through electronic media.

Tumor Boards: Oncology Tumor Boards provide a forum where MCA-member clinicians can receive input on individual patient cases from a multi-disciplinary team of clinicians and basic scientists associated with The University of Kansas Cancer Center. The Oncology Tumor Boards occur weekly and typically discuss individual cases, cancer treatment and management plan.

Disease Working Groups: MCA member oncologists may participate in one of seven disease working groups: Breast; Head & Neck; Gastrointestinal; Genitourinary; Brain; Lung and Hematological Malignancies. Group meetings are held on a weekly or monthly basis, depending on the group schedule.

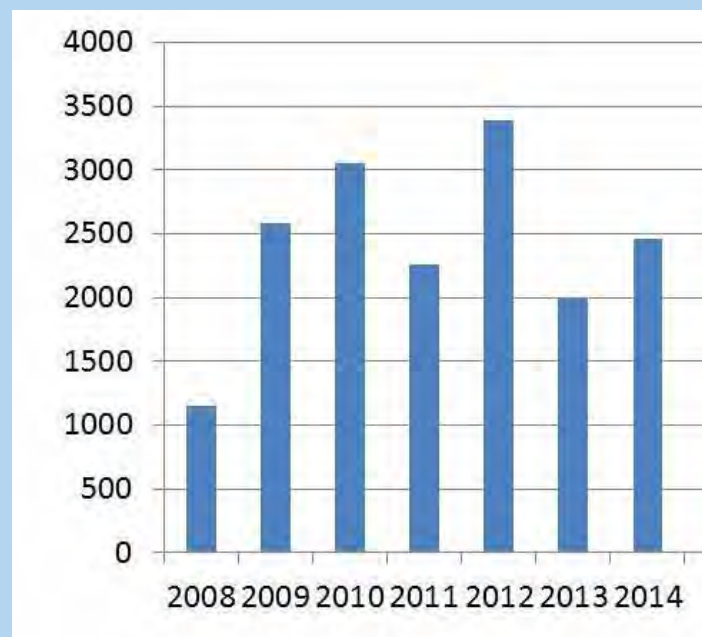
Clinical Research Education: MCA member research staff are invited to participate in clinical research education seminars held by the University of Kansas Research Institute. Topics are geared toward staff in the research coordinator role and cover a range of topics including Good Clinical Practice, data management, code of federal regulations, and patient recruitment and retention strategies.

Oncology Nursing Society's Chemotherapy and Biotherapy Course: This course provides nurses with a comprehensive overview of chemotherapy and biotherapy and includes information on newly approved agents to keep nurses apprised of the latest developments in drug therapy. The contact hours earned from this educational program qualify for initial oncology nursing certification and renewal via ONC-PRO. This course is currently offered online. MCA underwrites member participation.

Continuing Medical Education Credits: The KU Medical Center Office of Continuing Education is accredited by the Accreditation Council for Continuing Medical Education to provide continuing medical education for physicians. The number of credits issued varies per program. The MCA sponsors oncology-specific continuing medical education credits throughout the year. These CME credits are provided either free or at a discount for MCA members.

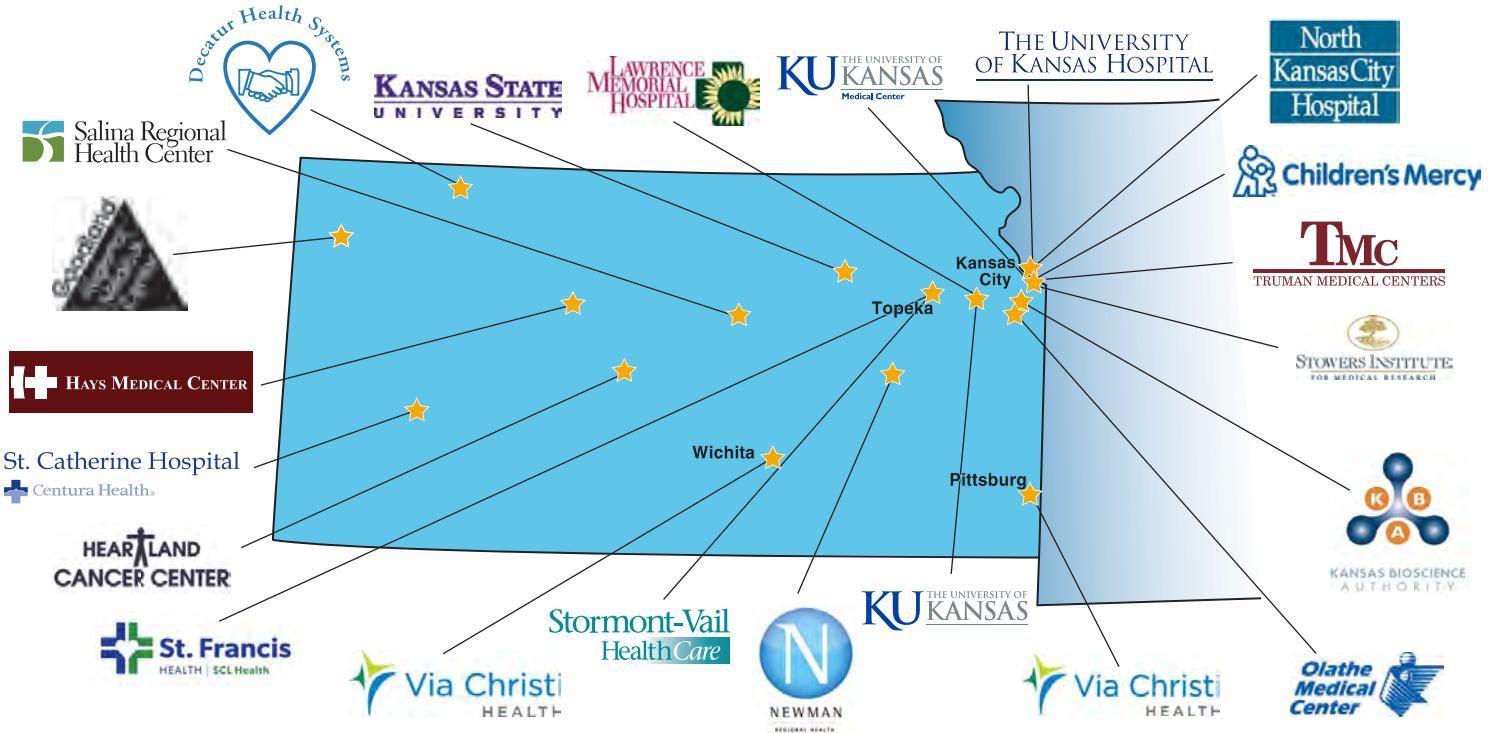
Continuing Nursing Education Credits: The University of Kansas School of Nursing is accredited as a provider of continuing nursing education by the American Nurses Credentialing Center's Commission on Accreditation. Throughout the year, the MCA sponsors oncology-specific continuing nursing education credits. These CNE credits are provided either free or at a discount for MCA members.

CONTINUING EDUCATION 2008-2014



■ # of CEs earned by MCA member medical professionals

MEMBERSHIPS



TYPES OF MEMBERSHIPS

Currently, the MCA offers four membership opportunities:

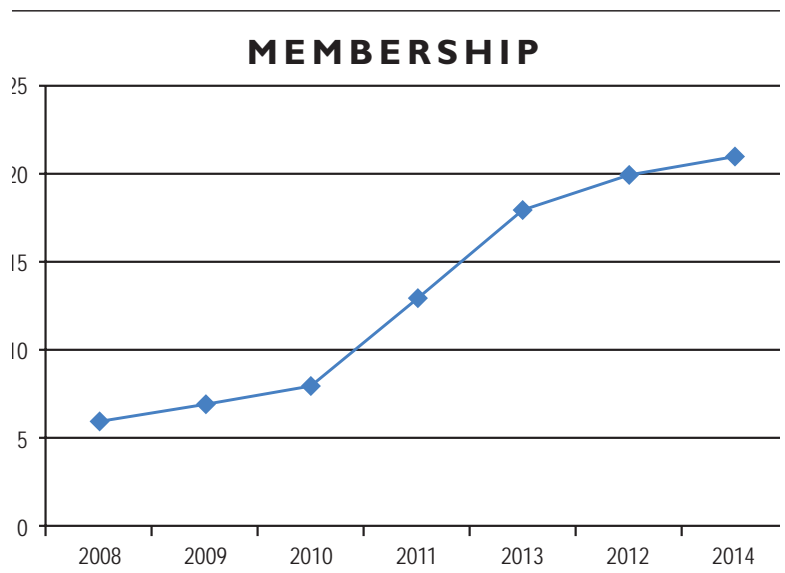
- Community Member
- Clinical Trials Member
- Major Clinical Research Partner
- Partners Advisory Board

More details on the features and requirements are provided for each membership category at www.midwestcanceralliance.org.

In January 2008, the Midwest Cancer Alliance started with five founding members unified by one mission: give individuals impacted by cancer more options close to home. Since then, the MCA has expanded to include 21 members across the region at four levels of membership.

The MCA receives financial support from a number of sources including: The University of Kansas Cancer Center, membership fees, grants, and donations from community and corporate organizations and individuals.

Over the past five years, the State of Kansas has provided up to \$5 million per year to The University of Kansas Cancer Center to support and maintain NCI designation. The University of Kansas Cancer Center provides up to 50% in matching funds for Kansas members' annual dues, as well as advance clinical trials and support outreach and education programs.



BENEFITS

BENEFITS OF JOINING

ONCOLOGISTS

- Increases access to innovative clinical trials
- Enhances network of research and clinical oncologists
- Increases access to consultative services and second opinions
- Provides latest evidence-based guidelines
- Provides continuing medical education opportunities

HOSPITALS

- Increases visibility and recognition as a center doing research
- Supports market share growth by retaining patients in the community
- Enhances ability to recruit and retain outstanding cancer physicians, nurses, and support staff
- Provides access to network IRB and reduces administrative burden for clinical trials

CANCER CARE PROFESSIONALS

- Enhances network of cancer care professionals working together
- Increases access to comprehensive cancer prevention, screening, diagnosis, care information and resources
- Provides the latest information on cancer care
- Improves the usage of regional cancer data
- Increases opportunities to expand knowledge base
- Provides continuing professional education opportunities

CANCER PATIENTS

- Advances comprehensive treatment locally
- Offers multidisciplinary care for every diagnosis
- Allows access to cancer clinical trials
- Improves access to cancer screening and prevention
- Second opinions via telemedicine

COMMUNITIES

- Helps attract and retain top oncology-trained practitioners in rural areas
- Reduces the “brain drain” of talented medical professionals from Kansas
- Creates and maintains jobs
- Spurs related economic development



Photo: Sunflowers on the Brack Farm by Mark Mingenback, St. Rose Health Center, Great Bend, KS



www.midwestcanceralliance.org

More options, close to home.