Collaboration is a word you see and hear over and over again at the Midwest Cancer Alliance. Since our founding in 2008, the MCA has built alliances with hospitals, medical professionals and research organizations across the Midwest. In the past 18 months, our network of 20 members has grown to include Citizens Medical Center, Inc. in Colby, Kansas. In addition, MCA-member patients have access to an expanding array of clinical trials and we continue working in partnership with our members to help promote awareness of clinical trials and increase accruals through joint marketing and public relations campaigns.

One of our oldest and most notable collaborations is with the Kansas Masonic Foundation (KMF). A partner in cancer screenings since 2003, KMF recently announced a $5 million endowment campaign to further support the MCA’s cancer prevention and research initiatives. In recognition of this significant commitment, MCA’s name will change to the Masonic Cancer Alliance once the endowment reaches its goal.

The patient research advocacy network, PIVOT – Patient and Investigator Voices Organizing Together – is another exciting, new partnership. It is one of the few advocacy networks located at a cancer center that offers cancer survivors the opportunity to meet regularly with scientists to share suggestions and ideas to help research better meet patients’ needs and improve quality of life.

MCA is now supporting KPPEPR – Kansas Patients and Providers Engaged in Prevention Research. This practiced-based research network of medical providers works together to solve problems of health care delivery in their communities. KPPEPR’s primary focus is on projects that impact rural and underserved communities.

Collaboration is also central to the education and outreach work we do. Each year, MCA-member medical professionals across the region utilize MCA’s educational programs and resources. In addition, thousands in rural communities have been helped through MCA-member partnerships on services like free cancer screenings, health and wellness programs, the Pool Cool sun safety initiative and psycho-social oncology services like MCA’s tobacco cessation program.

The Survivorship Transition Clinic partnership between The University of Kansas Cancer Center and Children’s Mercy is another great example of MCA member teamwork. Since its opening in 2014, the clinic has tripled in size to accommodate the growing number of pediatric cancer survivors and is involved in innovative research projects like the TLC4Survivors nutrition study.

Finally, one of our newest collaborations provides hospice support services in remote, rural areas using iPad technology. The iPads give Hospice Services, Inc. patients in isolated sections of Kansas easy access to virtual communication with hospice caregivers and cut down on the long, time-consuming drive.

That word – collaboration – will be even more evident as we prepare for MCA’s 10th anniversary in 2018. So stay tuned for news of more partnerships and projects aimed at improving detection, treatment, and survivorship in the Heartland.

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

Gary C. Doolittle, M.D.
Improving Clinical Trial Conversations Between Doctors and Underserved Cancer Patients

According to the National Institutes of Health, less than 2 percent of current cancer clinical trial participants are non-white and fewer than 5 percent are from rural communities. Due to such low representation, the degree to which communications that help improve understanding of clinical trials and encourage more participation among underserved populations and, subsequently, how to best communicate the purpose and function of clinical trials to these audiences1 is unknown. The hope is that the study’s endeavors were unaware of clinical trials as a potential treatment option, while others had heard of them but didn’t understand them. “Only a small minority could explain what a clinical trial was,” Erba said. However, many had a generally positive attitude towards them. Nearly 30 percent had a positive perception, but about 25 percent perceived trials as a last-resort treatment option. Some expressed concern about the trials’ safety, though participants reported that their doctors were a very important source of health information.

In order to explore knowledge, attitudes and behaviors relating to cancer clinical trials, the researchers first conducted a series of focus groups with oncologists and nurses and held interviews with 64 current and former cancer patients from rural and urban communities in the MCA network. To assess the opinion and attitudes of the general public, the researchers conducted an online survey distributed through social media. Most of the participants in these research endeavors were unaware of clinical trials as a potential treatment option, while others had heard of them but didn’t understand them.

Next, the research team developed two sets of culturally-sensitive messages that tailored for cancer patients from rural and urban communities to inform them about clinical trials and encourage them to ask their doctors about treatment options. The research team also developed messages tailored to doctors and nurses to remind and encourage them to discuss clinical trials with their patients. The six-month intervention started in mid-February in both mid-February in both rural and urban clinics in Kansas, the Midwest and the United States. The intervention includes printed displays, patient hand-outs as well as dedicated video clips.

The study is accessible online at: Clinical Trials Communications, 5, pp.72-79.

1Geana, M., Erba, J., Krebill, H., Doolittle, G., Madhusudhana, S., Qasem, A., Mugur Geana, M.D., Ph.D., principal investigator of the study and director of KUCC’s Health Communication Research Shared Resource and of KU’s Center for Excellence in Health Communication to Underserved Populations, noted, “In addition to the mass communication efforts aimed at patients, we will actively engage oncologists and provide them with dedicated informational tools and training to support and promote their clinical trial participation decisions.”

The six-month intervention started in mid-February in both participating cancer clinics, The Richard & Anneette Bloch Cancer Research Institute at Truman Medical Centers in Kansas City, Missouri and The Tammy Walker Cancer Center in Salina, Kansas. The intervention includes printed displays, patient hand-outs as well as dedicated video clips. Next, the researchers began to conduct a series of participatory seminars. The seminars aimed to assess understanding of cancer clinical trials among healthcare providers and to measure the effectiveness of the messages in terms of awareness and understanding of clinical trials, patient-provider discussions about clinical trials, and enrollment in clinical trials. As personalized medicine becomes more commonplace, research like this can help us ensure that clinical trial results are meaningful for everyone, regardless of their income level or address.”

“Participation in cancer clinical trials has traditionally been very low across the whole country,” said Joseph Erba, Ph.D., assistant professor at the William Allen White School of Journalism & Mass Communications and study co-investigator. “It’s even lower among certain minority populations, who are medically underserved to start with. Most of the clinical trial enrollment literature we now have does not consider these populations. In this study we do, plus we focus largely on the Midwest and how that compares and should differ based on participants’ identities.”

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Psyched About Survivorship

Over the past two years, Midwest Cancer Alliance psychiatrists, Susan Krigel, Ph.D., has launched several new cancer prevention and survivor support programs that MCA members can offer to their patients. 

Towards the end of 2014, Krigel kicked off a free smoking cessation program via Interactive Televideo. Based on a patient-centered program developed by Mayo Clinic, the program was presented in eight sessions over a three-month period. Since then, MCA members including Olathe Health, Salina Regional Health Center, St. Francis Health, St. Catherine Hospital, Truman Medical Centers, and Stormont-Vail Health have offered the program in their communities. By the end of last year, 79 participants had registered for the program.

In 2016, Krigel received a grant from Susan G. Komen Kansas for a breast cancer survivorship program in the southwest region of the state. She partnered with St. Catherine Hospital and St. Catherine Breast Center nurse, Heather Wright-Renick, RN, “Pink Platoon was just what we needed,” said breast cancer survivor Nancy Bieker of Garden City, Kansas. She added, “The session was very well attended…which goes to show we are all hungry for up-to-date information.”

According to St. Catherine Breast Center nurse, Heather Wright-Renick, RN, “Pink Platoon was just what we needed,” said breast cancer survivor Nancy Bieker of Garden City, Kansas. She added, “The session was very well attended…which goes to show we are all hungry for up-to-date information.”

Krigel recently received additional funding from Komen that will allow her to offer Pink Platoon in several more member locations over the next few years.

Hospice in the Palm of Your Hand

Using technology to provide supplemental hospice service in remote, rural areas is not new to the University of Kansas Medical Center. In fact, in 1998, Gary Doolittle’s team at KU Medical Center piloted one of the first tele-hospice (TH) programs in the country using large videophones. Since then, the program has evolved into a hand-held, tablet-based program like this all the more possible for underserved populations in remote, rural areas as well as urban areas in the future.

As the program rolls out in 2017, personnel at HSi will utilize the iPad with HIPAA-compliant, secure videoconferencing to connect in many ways with other hospice staff, patients, caregivers, and families. Examples of how the iPad will be used include staff orientations, weekly interdisciplinary team meetings, connecting a hospice patient to an out-of-state family member to help facilitate communications, honoring veterans with “virtual veteran pinning” and reconciling medication with the hospice patient and the patient’s family present. Professionals—professional virtual consultations connect patients and nurses to the HSI medical director as well as specialists. Telehospice’s cost savings in travel alone are compelling, with HSI staff covering 15,322 square miles across two time zones.

“We see this as an amazing hospice triage tool that connects families, patients, caregivers and health care professionals,” said Sandy Kuhlman, executive director of HSI.

The long-term goal is to utilize the iPad in hospice patient homes to aid in symptom assessment and provide additional support for both patients and caregivers, explained Ashley Spalding, MCA’s tele-oncology project manager. Spalding noted that these technology-based evaluations can also help hospice nurses quickly determine if an in-person visit is necessary, which has the potential to reduce travel and improve efficiency, in both rural and urban areas.

While telehealth visits are not intended to replace traditional hospice visits, the service means patients and caregivers will have hospice support, quite literally, in the palm of their hand.
Nearly 7,000 Kansas residents have attended the Masonic screenings over the past few years.

Cancer Screening Helps Pilot Avoid Turbulent Health

Over the past 17 years, Randy Pedersen, a University of Kansas pilot from St. Marys, Kansas, has flown MCA staff and University of Kansas Medical Center physicians to dozens of MCA–member and Kansas Masonic Foundation screenings across the state. The free screenings have been attended by thousands from rural communities.

On average, 20 percent of those screened were advised to see their local doctor because a possible health issue was spotted during the screening. In 2016, Pedersen became one of the 20 percent.

“When I flew the team to Goodland last January I hadn’t planned to participate in the screening,” admitted Pedersen. “But my wife had recently noticed a funny-looking mole on my back, so at the last minute, I decided to have them take a look at it as I was waiting to fly the crew back to Kansas City.”

At that time, KU Medical Center dermatologist Rachel Pflederer, M.D., advised Pedersen to keep an eye on the mole. When his wife noticed further change in the shape of the mole, Pederson was again screened by Pflederer when he flew the team to Salina in May. After the May screening, Pflederer urged him to visit his local physician.

“Melanoma can develop in just weeks,” noted Pflederer. “It’s important to keep a close eye on changes to your skin.”

Pedersen’s dermatologist in Topeka was Joseph Gadzia, M.D. Gadzia, another KU Medical Center graduate, diagnosed early-stage melanoma and recommended immediate removal of the cancer.

“When it comes to skin cancer,” said Gadzia, “the sooner it is treated, the better your chances of a good outcome.”

Pedersen was flying again the next day and has had no further issues since the surgery. However, Pedersen plans to stay vigilant. He and others across the Midwest will have plenty of opportunities with more Kansas Masonic Foundation screenings planned for 2017.

“You can bet that I will be visiting with those screening docs again every year or two,” promised Pedersen.

Cancer Screening Collaboration

The Kansas Masonic Foundation hosted 24 free cancer screenings in 2015, 26 screenings in 2016 and is currently gearing up for several dozen screenings in 2017.

The foundation conducts the screenings in partnership with the Midwest Cancer Alliance (MCA), the outreach division of The University of Kansas Cancer Center and KU Medical Center medical staff. According to Brooks Grenstein, the outreach director for MCA, nearly 7,000 Kansas residents have attended the Masonic screenings over the past few years. The events include free skin and prostate cancer screenings, facial sun damage assessments and bone density tests.

According to the Centers for Disease Control (CDC), skin cancer is the most common form of cancer in the United States. Nearly 6,500 Americans are diagnosed with some form of skin cancer every day, and more than 200 of those are diagnosed with melanoma, the deadliest form of skin cancer. Tragically, there are almost 10,000 Americans who die of skin cancer every year, according to CDC. This shows that Kansas has its own share of skin cancer in the United States.

“When we’re able to catch potential problems early on with screenings like these it can make a big difference in successful treatment,” said MCA Medical Director, Gary Doolittle, M.D.

“There are many more Kansas communities who can benefit from a service like this,” noted Robert Steenly, director of the Kansas Masonic Foundation. “The foundation is already working with our Lodges to offer more of these life-saving screenings in the years ahead.”

In addition to funding screenings at local Lodges for more than 15 years, the foundation created The Kansas Masonic Cancer Institute. The foundation also developed health initiatives like the Bob Dole Prostate Cancer Research Fund and the Oncology Nurse Navigator and Psychosocial Oncology Endowments at KU Medical Center over the past few decades.

“Our health partnership with the Kansas Masons is having an impact on thousands of lives.”

– Roy Jensen, M.D., Director of The University of Kansas Cancer Center and the Kansas Masonic Research Institute
Early results show that all participants increased consumption of fruits and vegetables. "After completion of treatment, childhood cancer survivors are at increased risk for nutrition-related problems," explained Surveillance Transition Clinic manager, Kyle Almen, RN. She added, "Educating survivors to improve their diet and engage in exercise gives them some control over their health."

The feasibility study, called TLC4Survivors, was conducted in two 12-week phases. The first took place in the spring of 2016 followed by another phase in the fall. A total of 16 cancer survivors participated.

According to KU Medical Center study coordinator, Rebecca Mount, MS, RD, all participants in the small-scale study received iPads loaded with nutrition and exercise information as well as fitness trackers. The participants were then divided into two groups, half participating in group exercise sessions and health coaching remotely via video conferences on the iPads and the other half received supplemental information but no face-to-face coaching.

Data from the study is still being compiled, but preliminary reports indicate some positive changes. "Early results show that all participants increased consumption of fruits and vegetables, with an even greater increase among the participants that received coaching," said Mount.

"PIVOT empowers patients and helps us advance quality cancer research and care," said Ray Jensen, Ph.D., KU Cancer Center director. Kansas City resident Cheryl Jernigan, a breast cancer survivor and lead investigator of a study designed to encourage cancer survivors to increase healthy lifestyle habits, MCA assisted with study recruitment. The study's lead investigator, Cheryl Gibson, Ph.D., and her team are hopeful that the results will lead to opportunities for additional grant funding that will allow them to expand the study.

By the start of its third year of operation, the BioBank at Truman Medical Centers (TMC) had enrolled an additional 100+ patients into its collection of data, blood and tissue samples gathered for the purpose of cancer research. TMC has also added several new initiatives in the past 18 months. The first was the development of an infrastructure that allows fresh tissue to be delivered directly to research labs. This capability gives TMC and its patient population the opportunity to contribute new initiative allows patients going through specimens. As a result, longitudinal blood draws are collected between each cycle of therapy, which is helpful for research on lymphomas. As Jernigan put it, "More survivor voices and more researcher interactions mean more solutions."
Sun Safety Program
Reaching Pools Across Kansas

Pool Cool, a sun safety program coordinated by Midwest Cancer Alliance and Kansas Cancer Partnership, has been recognized by the Centers for Disease Control as a successful cancer control program.

Pool Cool trains swim instructors at local pools to discuss sun safety during children’s swim lessons. Pool Cool also provides sunscreen, sunglasses, and UV wristbands that the instructors pass out during the lessons. Because Pool Cool reaches children through their swim instructors — people they already know and trust — children are more likely to listen and apply what they learn.

In fact, studies show that participants have significantly better sun protection habits than their peers. Children who complete the program seek shade more often and use sunscreen more regularly. Parents are also more likely to practice sun safety after their children participate in the program.

Officials in Kansas have embraced the program as a way to help the state’s residents protect themselves from skin cancer.

Twenty-one pools in the Kansas City area participated when the program began in 2014. By 2016, more than 50 pools across the state had joined.

“We have participated in the Cool Pool program for 2 years,” explained Lori Madaus, aquatic supervisor for the City of Lawrence, Kansas. “The swim lesson instructors use the sun safety lessons to educate our young swimmers in sun safety.”

According to program coordinator, Ashley Adorante, the ultimate goal is to give aquatic staff the tools they need to provide sun safety at every pool in Kansas.
Since our inception, Midwest Cancer Alliance (MCA) has worked with members to build a clinical trial infrastructure that enhances their ability to provide clinical trials as an option to patients in their own community. Clinical research partners of the MCA have access to NCI trials as well as studies developed at The University of Kansas Cancer Center.

**Clinical Trial Accruals**

Recently, two breast cancer treatment studies were developed at The University of Kansas Cancer Center and have been opened at MCA member locations. Twelve percent of the individuals enrolled on those two breast cancer studies were placed on study by MCA member physicians. This allowed the women to stay close to home while still having access to breast cancer treatment studies developed at The University of Kansas Cancer Center. In addition to accruing to treatment trials, members have focused on partnering with population and health communication researchers.

**Partners Advisory Board Spotlight**

For almost 10 years, MCA’s Partners Advisory Board Members have championed collaborative research and provided substantial financial support for the new research initiatives. The new research projects Children’s Mercy has initiated through the MCA Partners Advisory Board since 2010 are excellent examples of these efforts. These studies have ranged from studying tumors to understanding the needs of adult survivors of pediatric cancers. Midwest Cancer Alliance applauds the commitment of the Partners Advisory Board and Children’s Mercy to advancing research and clinical trial access across the Heartland.

**More options. Close to home.**

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