Incorporating the 2014 Cancer Registry Statistical Review











THE UNIVERSITY OF KANSAS Cancer Center

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# THE PROMISE OF DISCOVERY THE POWER OF CARE

Nationally recognized for the highest quality cancer care and research



# CHAIRMAN'S REPORT

JOSHUA M.V. MAMMEN, MD, PHD, FACS



Cancer Committee Chair Joshua M.V. Mammen MD, PhD, FACS

I am pleased to share our 2015 Cancer Center Annual Report. The American College of Surgeons' Commission on Cancer (CoC) has more than 1,500 participating hospitals in the United States and Puerto Rico. This represents only 30 percent of all healthcare institutions but more than 70 percent of all new cancer patients. The CoC provides important metrics and tools for cancer centers to improve quality and personalize cancer care.

CoC accreditation signals to patients access to the full scope of subspecialty care and services. For patients and their families, accreditation is an important measure of quality care and a commitment by The University of Kansas Cancer Center to continually improve the care provided to cancer patients.

The University of Kansas Cancer Center was recognized in this last year for its excellent care of cancer patients. The U.S. News & World Report rankings once again listed The University of Kansas Cancer Center as one of the best cancer

programs in the country. For the second consecutive year, The University of Kansas Hospital was recognized in all 12 medical and surgical specialty categories of patient care, a remarkable achievement.

As the number of patients we care for continues to increase, our need for additional facilities grows. This leads The University of Kansas Hospital to look to the future. To that end, fundraising efforts are underway to build a new inpatient facility, currently named Cambridge North Tower. The new building will contain cutting-edge surgical, interventional and diagnostic facilities to enable our physicians to continue to provide the most up-to-date care for our cancer patients. The new tower is anticipated to open in 2017.

The University of Kansas Cancer Center is dedicated to the eradication of cancer. Over the last year in particular, we have been able to offer our patients many new options for cancer treatment and prevention. As we continue to pursue this goal together, we will continue to conduct new research, translate our findings into innovative therapies and investigate new ways to prevent and diagnose cancer. Together, we will continue to ensure that the patients and families we serve receive the highest level of care from diagnosis through treatment and survivorship.



Proposed Cambridge North Tower

# CANCER REGISTRY REPORT

The University of Kansas Cancer Registry operates under the direction and guidance of the Cancer Committee and is located within Health Information Management. The Cancer Registry at our facility became accredited by the American College of Surgeons in 1934, and has maintained accreditation since. The reference date for the organization is 2004; however, the current electronic database contains data pertaining to patient demographics, cancer diagnoses, treatment information, staging and outcomes that go back to 1947. More than 87,991 cases have been added to the electronic registry for the accession years of 1947 through 2014. The registry participates in the American College of Surgeons Commission on Cancer Approvals Program. The Commission on Cancer, or CoC, provides standards and program review of healthcare facilities participating in its program.

The Cancer Registry has a staff of 17 certified tumor registrars (CTRs). Cancer registrars collect and analyze all reportable and supplemental data; document Cancer Committee attendance and provide a cancer registry report for each meeting; document tumor conference information; supply reports of database information to medical and administrative staff; and report all cases to the Kansas Cancer Registry. Missouri cases are sent to the Missouri Cancer Registry. The registry also follows patients annually to determine health changes and provide information for survival and outcomes data.

The registrars collectively are members of the National Cancer Registrars Association (NCRA), the Kansas Cancer Registrars Association (KCRA), the Kansas City Area Tumor Registrars Association (KCATRA) and the Missouri State Tumor Registrars Association (MOSTRA). All participate in educational events annually to maintain certification status, and the CTRs also attend a regional or national cancer conference at least every three years.

In 2014, 6,113 new cases were added to the registry and 5,444 were analytic (cases diagnosed and/or treated by one of the facilities of The University of Kansas Cancer Center for the patient's first course of treatment).

Cancer Registry data is available for multiple uses, including reporting results and evaluating quality care, as well as for research and educational purposes. Periodic follow-up is an important function of the registry. It increases the likelihood that patients will receive appropriate medical care for early detection and treatment of recurrent or new cancers. Early detection can potentially improve survival. Information obtained through follow-up provides researchers and clinicians with a means to study the disease process and efficacy of treatment modalities.

The follow-up rate for all analytic patients from the Cancer Registry reference date of 2004 is 87.14 percent. The CoC requires this rate to be at least 80 percent. The follow-up rate for analytic patients diagnosed within the last five years is 91.07 percent, which also meets CoC requirements for the five-year rate.

The Cancer Registry assists in the collection of the cancer conference data. Tumor conferences were presented on a weekly, bimonthly or monthly basis by an interdisciplinary team consisting of physician representatives from many different departments. The University of Kansas Cancer Center had 12 different cancer conferences in 2014. These events were tracked to provide consultative services to patients and help educate the medical staff and other healthcare professionals. National treatment guidelines, staging, prognostic indicators and clinical trial options are also discussed at these conferences. There were 287 tumor conferences held in 2014, which included multidisciplinary, breast, GI, lymphoma and myeloma, head and neck, thoracic, bone marrow, thyroid, neuro-oncology, genitourinary (GU) and melanoma. Sarcoma was a new conference added and tracked in 2014. A total of 1,422 cases were presented at these various conferences.

The Cancer Registry is staffed by the following Health Information Management personnel:

#### Management

- Theresa Jackson, RHIA director
- Tim Metcalf, BS, CTR manager
- Ashley Wagner, CTR lead registrar

#### Registrars

- Kerry Barkman, RHIT, CTR
- Christine Bartlett, RHIT, CTR
- Elaine Casper, RHIT, CTR
- Cari Dobosz, RHIT, CTR
- Ian Duff, BS, RHIA, CTR
- Kathrine Greene, RHIT, CTR
- Sandra Haenchen, RHIT, CTR
- Marsha Klein, BS, RHIT, CTR
- Joyce Knapp, RHIT, CTR
- Garrett Neiss, RT, CTR
- Mary Beth Piranio, BA, RHIT, CTR
- Andrea Reynolds, RHIT, CTR
- Marcelo Saculles, RHIT, CTR
- Terry Sigmund, CTR
- Marji Smith, RHIT, CTR

#### Volunteer/Registrar-in-Training

• Julie Mammen

# **CP3R** - CANCER PROGRAM PRACTICE PROFILE REPORTS

Commission on Cancer Standards 4.4 and 4.5 require The University of Kansas Hospital performance rates for the measures listed in Table 1, which reflect our benchmark compliance rates. This offers the opportunity to review data to ensure our performance rates reflect the quality care that we provide. The Cancer Committee reviews and has the opportunity to modify treatment strategies in order to benchmark our alignment with national quality guidelines and recommended best practices, which will allow us to assure optimal patient outcomes. Below are the measures we reviewed in 2014. Breast conservation is a "surveillance" measure only, where treatment vs. outcome is not fully assessed. In addition, performance rates for this measure are impacted by patient treatment option preference. We have met or exceeded all Accountability and Quality Improvement goals.

Measure	Measure Type	Goal	2011	2012	2013
Breast					
Image or palpation-guided needle biopsy (core or fine needle aspirate) of the primary site is performed to establish diagnosis of breast cancer.	Quality Improvement	80%	99.50	99.40	98.60
Tamoxifen or third generation aromatase inhibitor is recommended or administered within 1 year (365 days) of diagnosis for women with AJCC T1c or stage IB-III hormone-receptor-positive breast cancer.	Accountability	90%	95.70	93.90	95.30
Combination chemotherapy is recommended or administered within 4 months (120 days) of diagnosis for women under age 70 with AJCC T1 cN0, or stage IB-III hormone-receptor-negative breast cancer.	Accountability	90%	91.80	94.50	98.90
Breast conservation surgery rate for women with AJCC clinical stage 0, I, or II breast cancer.	Surveillance	Not Applicable	51.60	50.50	48.00
Radiation is administered within 1 year (365 days) of diagnosis for women under age 70 receiving breast conservation surgery for breast cancer.	Accountability	90%	92.10	93.00	94.80
Radiation therapy is recommended or administered following any mastectomy within 1 year (365 days) of diagnosis of breast cancer for women with >= 4 positive regional lymph nodes.	Accountability	90%	91.70	95.60	90.60
Colon					
Adjuvant chemotherapy is recommended or administered within 4 months (120 days) of diagnosis for patients under age 80 with AJCC stage III (lymph node positive) colon cancer.	Accountability	90%	100.00	93.80	90.00
At least 12 regional lymph nodes are removed and pathologically examined for resected colon cancer.	Quality Improvement	85%	92.60	96.90	95.10
Rectum					
Preoperative chemo and radiation are administered for clinical AJCC T3N0, T4N0 or Stage III; or postoperative chemo and radiation are administered within 180 days of diagnosis for clinical AJCC T1-2N0	Quality Improvement	Not Applicable	100.00	83.80	92.00

#### TABLE 1

with pathologic AJCC T3N0, T4N0 or Stage III; or treatment is recommended for patients under age 80

receiving resection for rectal cancer.

## 2014 Research Roundtables

The University of Kansas Cancer Center and the Kansas Masonic Cancer Research Institute conduct a variety of educational activities. These include research roundtables, tumor conferences, symposia and interdisciplinary conferences. In addition to providing supplemental education to our students, physicians and researchers, the purpose of these activities is to achieve a greater level of collaborative research and multidisciplinary interaction.

#### MARCH 1

Chao Huang, MD, FACP Faris Farassati, PhD, PharmD Lauren Byers, MD Takefumi Komiya, MD PhD Nirmal Veeramachaneni, MD Cherie-Ann Nathan, MD, FACS Chris Lominska, MD "Lung and Head & Neck Symposium"

#### MARCH 29

Suman Kambhampati, MD Sid Ganguly, MD Brea Lipe, MD Joseph McGuirk, DO Anaadriana Zakarija, MD Tara Lin, MD "Current Updates in Hematologic Diseases"

#### APRIL 12

Joseph McGuirk, DO David Porter, MD Sid Ganguly, MD Sergio Giralt, MD Asad Bashey, MD, PhD Sunil Abhyankar, MD Mary Flowers, MD "Advances in Blood and Marrow Transplantation" JULY 7 Ruben Mesa, MD "Myeloproliferative Neoplasms"

AUGUST 2 Joaquina Baranda, MD Peter Van Veldhuizen, MD Mohammad Jahanzeb, MD, FACP Priyanka Sharma, MD Suman Kambhampati, MD Carol Fabian, MD "ASCO Review 2014"

#### AUGUST 14

Harry Erba, MD, PhD "Rethinking the Treatment of Older Adults with Acute Myeloid Leukemia: A Visiting Professor Lecture Series for Hem/Onc Fellows"

#### AUGUST 18

Rami Komrokji, MD "Optimizing Relationships with Hematologists and Primary Physicians for Best MPN Patient Practices"

#### **NOVEMBER 10**

Jeffrey Wolf, MD "Best Practices in the Treatment of Patients with Multiple Myeloma"

#### NOVEMBER 15

Philip Philip, MD Chris Lominska, MD Sean Kumer, MD Joaquina Baranda, MD Xinglei Shen, MD Mazin Al-kasspooles, MD Qamar Khan, MD Melissa Mitchell, MD Jamie Wagner, DO Michael Sabel, MD "Multidisciplinary Oncology Conference"

# **2014** TUMOR CONFERENCES

Type of Conference	Interval	Number of Conferences	Number of Analytic Cases Presented
Departmental: Head & Neck	Weekly	30	221
Departmental: Genitourinary(GU)	Bimonthly	19	68
Departmental: Thoracic	Weekly	44	287
Multidisciplinary	Weekly	36	59
Site-Focused: Bone Marrow/BMT	Weekly	43	253
Site-Focused: Breast	Weekly	30	73
Site-Focused: Gastrointestinal(GI)	Weekly	36	141
Site-Focused: Hemepath	Weekly	33	63
Site-Focused: Melanoma	Monthly	11	46
Site-Focused: Neuro-Oncology	Bimonthly	23	83
Departmental: Sarcoma	Monthly	6	28
Site-Focused: Thyroid	Monthly	11	100
Totals		322	1,422

# **2014** COUNTY DISTRIBUTION

Kansas by Place of Residence at Diagnosis	Missouri by Place of Residence at Diagnosis
Johnson: 20.38%	Jackson: 19.61%
Wyandotte: 8.0%	Clay: 8.75%
Leavenworth: 3.01%	Platte: 4.61%
Shawnee: 2.61%	Cass: 3.08%
Douglas: 1.73%	Buchanan: 1.41%
Other Kansas: 15.34%	Other Missouri: 9.73%
Total Kansas: 51.07%	Total Missouri: 47.19%

All Other States: 1.69% Unknown County or State: 0.05%

# THE UNIVERSITY OF KANSAS HOSPITAL – 2014 PRIMARY SITE TABLE\*

PRIMARY SITE	ANALYTIC	NONANALYTIC	TOTAL
Oral Cavity	208	14	222
Lip	2	0	2
Oropharynx	3	1	4
Hypopharynx	6	0	6
Digostivo System	150 <b>91</b> 4	õ 00	158
Esophagus	60	4	<b>902</b> 64
Stomach	59	7	66
Colon	163	32	195
Anus/Anal Canal	19	2	21
Liver	155	10	165 176
Other	76	14	90
Respiratory System	584	51	635
Nasal/Sinus	18	2	20
Larynx Lung/Bronchus	509	34	543
Other	12	1	13
Blood & Bone Marrow	485	60	545
Leukemia Multiple Myeloma	262 145	51 14	293 159
Other	78	15	93
Bone	37	5	42
Connect/Soft Tissue	79	13	92
Skin	239	37	276
Other	216	34	250
Breast	1,186	74	1,260
Female Genital	310	17	327
Cervix Uteri	48	1	49
Ovary	74	13	87
Vulva	18	0	18
Other Mala Carital	1/	80	18
Prostate	302	73	375
Testis	41	7	48
Other	8	0	8
Bladder	<b>404</b> 158	<b>84</b> 46	<b>488</b> 204
Kidney/Renal	237	38	275
Other	9	0	9
Brain & CNS Brain (Benign)	<b>243</b> 16	<b>42</b>	<b>285</b>
Brain (Malignant)	97	24	121
Other	130	13	143
Thyroid	153 112	<b>20</b> 12	173 124
Other	41	8	49
Lymphatic System	264	53	317
Hodgkin's Disease Non-Hodgkin	30 234	10 43	40 277
Unknown Primary	65	3	68
Other/III-Defined	22	6	28
Reportable by Agreement	0	22	22
All Sites	5 444	669	6 113

\*Includes malignant and reportable benign cases.

# 2014 STATISTICAL GRAPHS - ANALYTIC CASES



Class 00: Diagnosed here, all treatment elsewhere. Class 10-14: Diagnosed here, all or part of first-course treatment here.

Class 20-22: Diagnosed elsewhere, all or part of first-course treatment here.





## SEX DISTRIBUTION



#### SEER SUMMARY STAGE AT DIAGNOSIS (n=5,444)



## AJCC STAGE GROUP AT DIAGNOSIS\* (n=5,444)



\*Class 00 not included/required by CoC.

### AGE AT DIAGNOSIS (n=5,358)



## TOP FIVE PRIMARY SITES: AMERICAN CANCER SOCIETY STATISTICS



# MYCHART ACTIVE SIGN-UP QUALITY IMPROVEMENT

DEBBIE FERNANDEZ, LMLP, MHSA; HEATHER FIGARY, RN; TERRIE PIERCE, RN; KARLA TARTAGLIA, RN

THE UNIVERSITY OF KANSAS CANCER CENTER

Patient engagement continues to receive increased attention at a national level. One method to increase patients' engagement in their medical care is by utilizing patient portals; however the functionality of a patient portal is dependent on the number of active users. As a cancer center, we demonstrated optimal performance based on Meaningful-Use criteria for our ability to provide patients the ability to view, access and download medical information; yet, at the same time our Meaningful-Use data also indicated a gap between providing the ability to access the information and actual patient engagement. To improve our overarching patient engagement, we completed two qualityimprovement studies to address our ability to increase the number of patients who have an active patient portal (MyChart) status.

#### QUALITY STUDY 1

The first quality study was conducted by a group of masters of health services administration (MHSA) graduate students in collaboration with cancer center staff. The purpose of the study was to identify gaps and barriers related to patient engagement with the MyChart portal. Students utilized iPads in clinic to facilitate MyChart sign-up one-on-one with patients. Results of the study indicated that patients are interested in signing up (Figure 1). However, barriers identified related to patient and staff access to activation codes, introduction of the patient portal to patients, and lack of a standardized process led to gaps in workflow and patient sign-up. As a result of this study, the next step was to conduct a follow-up qualityimprovement study related to the creation of a standardized workflow.

#### QUALITY STUDY 2

The second quality study was conducted by a team of nurse managers in collaboration with the quality coordinator. The goal of this study was to identify the most efficient standardized workflow at every cancer center location to



FIGURE 1: MYCHART PATIENT SIGN-UP RATE

increase MyChart active status accrual. The planning stage involved identifying the top five barriers to the current process and developing a standardized workflow to test (Figure 2). The future state workflow was piloted at the Lee's Summit and Westwood BMT locations. Results of the study indicated higher active MyChart accrual at the pilot sites compared to other locations. As a result of this quality-improvement study, the future state workflow was implemented across all cancer center locations. A target benchmark based on 2013 U.S. Census Internet Use was set at 75 percent. Trending results indicate month-over-month improved active MyChart sign-up rates with patients (Figure 3). Results are shared monthly with frontline and leadership staff within the cancer center, and new barriers are identified as opportunities for continuous improvement.

#### ACKNOWLEDGEMENTS

Special thanks to our cancer center patients and staff, including Daniel Kenner, Julie Lawson, Jessica McClain and Dori Tompkins.

continues



FIGURE 2: MYCHART FUTURE STATE WORKFLOW





# MONITORING COMPLIANCE WITH EVIDENCE-BASED GUIDELINES – GLIOBLASTOMA REVIEW, 2014 CASE ANALYSES

MICHAEL E SALACZ, MD, DIRECTOR, BRAIN AND SPINE TUMOR PROGRAM

THE UNIVERSITY OF KANSAS CANCER CENTER

#### **GLIOBLASTOMA MULTIFORME (GBM)**

In adults, the most common, primary, malignant central nervous system cancer is glioblastoma, WHO grade IV. With an annual U.S. incidence of approximately 12,000 (according to Central Brain Tumor Registry of the United States), it is a "rare" cancer as designated by the National Cancer Institute. Treatment advancement has lagged compared to many other cancer types due to a variety of factors. These include: limited patient numbers, wide variability of cancer geno- and phenotypes between patients and within individual patients and difficulty in drug delivery across the blood-brain barrier. Unfortunately, the tumors are rapidly growing and highly invasive; as a result survival is short, averaging 14-16 months. Almost all patients ultimately die from tumor progression. Unlike a number of other cancers, with glioblastoma there are no screening tools to identify patients early and no serum or urine biomarkers to follow cancer burden and response to treatment.

#### Symptoms at Presentation

Symptoms which lead to initial patient presentation include headache, nausea/ vomiting, seizure, confusion, vision deficit and unilateral weakness/sensory loss. With a rapidly growing cancer like glioblastoma, progression over a period of days to a few weeks is typical. The low predictive value of the symptoms heralding an underlying glioblastoma, let alone any type of brain cancer, is challenging to the primary care physician and emergency medicine teams. Published data suggest that in adults the likelihood of new-onset seizure leading to diagnosis of brain tumor is only 2%-3%. And, having headaches severe enough to seek primary care attention and ultimately being diagnosed with a brain tumor has a likelihood of around 1 patient in 1,000. This rarity leads – appropriately in many patients – to more conservative treatment approaches before brain imaging is performed, thereby delaying diagnosis and more definitive treatments.

#### EVIDENCE-BASED GUIDELINES

Standard-of-care treatment for patients with glioblastoma continues to evolve. The use of involved-field radiotherapy has been accepted for decades as beneficial, albeit, potentially with the loss of cognitive function, while other treatment modalities have only more recently come to be accepted. The typical treatment approach is maximal safe surgical debulking of the enhancing component of the tumor. This treatment approach comes from retrospective data sets; prospective data randomizing patient to resection vs. small biopsy would not be ethical and will likely never be pursued. As a result, there remains tension between pushing the extent of resection vs. maximizing patient safety during surgery. Nonetheless, the present standard of care for this disease per National Comprehensive Cancer Network (NCCN) guidelines includes maximal safe resection (sometimes this is only a biopsy depending) on tumor location) followed by a course of radiotherapy. While the intraoperative use of carmustine wafers (BCNU), dependent on the patient's age and performance status, is indicated in the guidelines, the practice has fallen out of favor because of limited benefit, increased postoperative complications and potential downstream exclusion from clinical trials. If the patient is doing well physically and cognitively, the oral chemotherapy temozolomide is typically added concurrent with radiation. Postradiation, temozolomide is continued on a monthly pulse dosing schedule. To date, temozolomide is the only chemotherapy shown in a randomized trial to improve overall survival (from about 12 to 14.5 months – Stupp, NEJM, 2005). This large, multinational study showed temozolomide provided benefit in glioblastoma treatment, but the study had an age cutoff of 70 and excluded patients with poor function. Thus, the treatment of older adults and those with poor performance status remains unknown. Typically, for patients who have had debulking surgery or biopsy, reasonable options

continues

## Monitoring Compliance with Evidence-Based Guidelines – Glioblastoma Review, 2014 Case Analyses

include radiation with temozolomide, radiation alone, temozolomide alone or palliative/ supportive measures. This review focuses on the initial treatment of patients with glioblastoma. At present, there is no accepted second-line treatment option for patients at recurrence. Intervention can include repeat surgery, radiation and/or chemotherapy.

#### THE UNIVERSITY OF KANSAS CANCER CENTER GLIOBLASTOMA PATIENT POPULATION

Of interest, in reviewing our 2014 GBM population, we had the following distributions, which are consistent with nationally published numbers.



#### THE UNIVERSITY OF KANSAS CANCER CENTER GLIOBLASTOMA PATIENT POPULATION BY RACE, 2014

Race*	Number
White	60
Black	1
Asian	1
Oriental	0
American Indian	0
Other	0
Totals	62

\*NOTE: Asian includes Asian Indian, Pakistani and other Asian Oriental includes Chinese, Japanese, Filipino, Korean and Vietnamese Other includes all races not listed above and/or unknown

#### THE UNIVERSITY OF KANSAS CANCER CENTER GLIOBLASTOMA PATIENT POPULATION BY GENDER, 2014



#### continues

#### MONITORING COMPLIANCE WITH EVIDENCE-BASED GUIDELINES – GLIOBLASTOMA REVIEW, 2014 CASE ANALYSES

#### TREATMENT EVALUATION

Out of the 62 patients with glioblastoma diagnosed at our institution in 2014, 43 or just over 69% of patients were documented as receiving the most aggressive treatment strategy of maximal surgical debulking followed by radiotherapy with concurrent and adjuvant Temozolomide. In all patients who received chemotherapy within The University of Kansas Cancer Center system, temozolomide was the drug utilized. In five of the patients who received surgery, radiation and temozolomide, BCNU wafers were also utilized at the time of surgery. This demonstrates appropriate and aggressive treatment to battle this deadly form of cancer. Several patients also received palliative bevacizumab, an approved anti-angiogenic agent, along with the standard-of-care approach for symptom control.

Seven patients underwent surgery followed by radiation, but elected no chemotherapy. One patient developed bacterial meningitis postoperatively and underwent radiotherapy alone with ongoing antibiotic therapy. The remaining six patients had no documentation of chemotherapy; however, most were treated outside of The University of Kansas Cancer Center system and did not have documentation in our electronic medical record.

Three patients had radiation and temozolomide after limited biopsy, with no formal debulking surgery. After review, these cases all had documented unresectable tumors.

Only three patients had no cancer-directed treatments. One was due to tumor location and the other two were due to poor performance status and transition to palliative/supportive care with hospice.

Three patients underwent surgery followed by chemotherapy with no radiotherapy. One had failing performance status, so transport for daily radiation was problematic and not performed. Another chose not to pursue radiation due to lack of available radiation oncology services within reasonable travel distance from their home. The third patient, after informed discussion, elected not to pursue radiation therapy.

One patient had a partial course of radiation therapy only with no concurrent temozolomide. Treatment was limited due to a fall with a resulting subdural hematoma.

Two patients had surgery only, with one expiring prior to planned radiation and chemotherapy. The other had multifocal involvement and expired before any further treatment could occur.

#### SUMMARY

In summary, a review of data demonstrates appropriate treatment per American Brain Tumor Association and NCCN Guidelines was administered for our 2014 glioblastoma population. Striking from this data set is how ill many patients are at the time of diagnosis and how limited survival can be even with appropriately aggressive supportive care and intervention. Although all patients were treated in accordance with published guidelines, nearly one in three patients was unable to receive maximally aggressive anticancer therapy. There is a clear, urgent need for more effective antiglioblastoma therapies.

# NATIONAL CANCER INSTITUTE DESIGNATION

Central to The University of Kansas Cancer Center's vision to eliminate cancer in our region and beyond was achieving National Cancer Institute, or NCI, designation in June 2012. NCI designation signifies that our academic cancer center has attained the highest standards and that promising cancer research, leading to improved care and treatment, takes place in our community.

## THE NCI ACCREDITATION PROCESS

NCI designation is the highest recognition for an academic cancer center. It opens doors to additional research funding, provides related economic benefits and jobs to the community and brings the most advanced cancer care to patients.

With NCI designation, our region realizes a new level of excellence as a bioscience research center. It provides us the opportunity to more fully leverage research investments made by the University of Kansas and the Stowers Institute for Medical Research.

In addition, NCI designation drives growth across many related segments of the regional economy. Approximately 1,200 employees, including faculty, research support, clinical and administrative staff, are dedicated to cancer clinical care and research activities. We estimate that from 2006 to 2011, our pursuit of NCI designation created 1,014 regional jobs and had a regional economic impact of \$346 million. By 2016, we estimate the number of jobs created will reach 2,241 and the regional economic impact of NCI investments will total \$1.93 billion.

No other regional initiative has as much potential to simultaneously drive economic development and public health.

# How patients benefit from NCI Designation

Most importantly, NCI designation means patients in our region do not have to travel far to find the most advanced care and clinical trials. These resources are available close to home.

NCI-designated Cancer Centers recruit top physician-scientists. Patients receive the latest evidence-based treatments. Patients who are unresponsive to standardized treatments may have additional options provided through NCI Cancer Center-sponsored trials. Our patients receive access to the same promising therapies offered in clinical trials at other top NCI Cancer Centers.

Becoming the 67th NCI-designated Cancer Center is a milestone in our journey to ultimately eliminate cancer.

# CANCER PATIENT SUPPORT SERVICES

#### NURSE NAVIGATION SERVICES

Our nurse navigators guide patients from their first call through their treatment process and follow-up. They answer questions and offer emotional support every step of the way. Nurse navigators make sure patients are prepared to meet with specialists and their cancer care team by collecting medical records, getting orders for tests when needed and identifying support services for patients and their caregivers.

#### SOCIAL SERVICES

Our social workers assist patients in both inpatient and outpatient settings. In addition to helping patients and their loved ones cope with distress related to their cancer diagnosis and treatment, our social workers provide resources for lodging, transportation, home care services and financial concerns, including medication assistance programs. They also provide information on Social Security disability and Medicaid and make referrals to community resources that offer numerous classes and programs.

#### **PSYCHO-ONCOLOGY SERVICES**

Our licensed psychologists provide patients and their caregivers support for the mental, emotional and behavioral aspects of the cancer experience. They provide assessment, consultation and evidence-based therapeutic interventions and counseling for individuals, groups, families and couples. They also help patients adjust to the lifestyle and behavior changes that accompany cancer diagnosis, treatment and survivorship. Short-term crisis resolution and grief counseling for caregivers and family members are also available.

#### **NUTRITION SERVICES**

Our dietitians provide individualized nutrition care to patients and work with caregivers in helping patients achieve optimal nutrition at home. Our dietitians work closely with each patient's healthcare team to provide comprehensive care, with the goal of keeping patients strong, maintaining muscle mass, promoting healing, treating nutritional deficiencies and minimizing complications and side effects of cancer. Ultimately, the dietitian's goal is to promote overall better quality of life before, during and after cancer diagnosis and treatment through good nutrition.

#### **S**PIRITUAL SERVICES

We offer pastoral care/spiritual services for our patients and hospital visitors to help them meet their spiritual needs. Members of our spiritual care team are available on request to everyone. All of our spiritual care teams are ordained ministers and able to offer prayer, pastoral counseling and worship services.

### FINANCIAL COUNSELING SERVICES

Our financial counselors help patients navigate the cancer journey by understanding the costs of cancer and insurance implications, and the complex application process for Medicaid and other financial assistance programs. They also assist patients in securing financial benefits from these programs and from private health insurance. The Patients in Need Fund at Missys' Boutique at our Westwood campus helps uninsured and underinsured patients receive the boutique's cancer-related services and products at no charge.

#### EDUCATIONAL RESOURCE SERVICES

Our patient resource centers provide answers, resources and support for cancer patients, their families and the community. Staffed by an experienced oncology nurse, each center offers information about specific types of cancer, treatments, clinical trials and other cancer-related issues. A variety of cancer-related programs and educational classes are offered throughout the community as well. Others are available through televideo.

#### **P**RACTICAL AND EMOTIONAL SUPPORT GROUPS

Our staff facilitates support groups and educational programs for patients and families affected by gynecologic, breast, renal cell, head and neck, prostate and other cancers, along with groups for caregivers. Patients and families also receive information about community cancer support groups and agencies that provide practical and emotional support.

Turning Point: The Center for Hope and Healing in south Kansas City, a program of The University of Kansas Hospital, provides educational programs at different locations continues

## CANCER PATIENT SUPPORT SERVICES

throughout the greater Kansas City area at no charge. Topics include mind/body, movement, nutrition, art and more for all patients with chronic illnesses. It also offers programs for children of all ages and their family members.

#### **ONCO-REHABILITATION SERVICES**

Our onco-rehabilitation physiatrist works with cancer patients and caregivers in inpatient and outpatient settings to help them maintain and improve their functional abilities, alleviate pain, minimize fatigue and improve quality of life. Occupational therapists focus on helping patients with activities of daily living, and speech pathologists help patients who have difficulty with communication, cognition or swallowing.

#### **PERSONAL APPEARANCE SERVICES**

Missys' Boutique, located at our Westwood campus, is an accredited appearance center dedicated to helping patients overcome appearance obstacles with dignity and style. Services include bra and wig fittings. Products include breast forms, postsurgery bras and camisoles and a wide assortment of clothing and accessories.

#### **S**URVIVORSHIP SERVICES

Surviving cancer begins the day of diagnosis and continues every day after. Survivorship services include:

- Providing patients with treatment summaries
- Providing ongoing care of survivors and their caregivers
- Scheduling follow-up appointments
- Referring patients to appropriate support services to address late effects such as energy balance or cognitive concerns

#### FERTILITY PRESERVATION SERVICES

Cancer treatments result in fertility challenges following treatment. We provide fertility preservation services in which eggs and sperm are harvested from the body, preserved through freezing and transplanted back after treatment.

#### **P**ALLIATIVE CARE

Palliative care focuses on how well patients with a terminal illness can live better every day. We provide for the medical, emotional and spiritual needs of patients of all ages with illnesses at any stage. Outpatient services are offered through the Allen J. Block Outpatient Palliative Care Program.

### GENETIC COUNSELING

Through genetic consultation, we are able to help patients proactively. With a full assessment of risk factors and family history, we can better understand the underlying cause of a patient's disease. This allows us to more accurately predict the patient's response to treatment and create a highly individualized treatment plan.

#### PHARMACY PATIENT ADVOCATE SERVICES

We provide pharmacy patient advocates, or PPAs, who answer patients' questions or concerns, reorder medications and streamline payment processing.

#### SECOND OPINION SERVICES

We offer second opinions to provide patients and referring physicians the opportunity to receive multidisciplinary opinions and the confidence to begin treatment.

#### NATIONAL CANCER INSTITUTE CANCER INFORMATION SERVICE

The NCI Cancer Information Service provides the latest and most accurate information to patients, their families, the public and healthcare professionals. This national information and education network is a free public service of the NCI. Call toll-free 800-4-CANCER.

#### BIOSPECIMEN BANK

The Biospecimen Bank at The University of Kansas Cancer Center supports cancer research by serving as a bank for human tissues and fluids. Researchers use these biospecimens to study causes, prevention, detection, diagnosis and treatment of cancer. Find out how you can make a tissue or fluid donation by calling toll-free 855-211-1475.

## GLOSSARY OF TERMS

Accession number: A unique number assigned to each patient entered into The University of Kansas Hospital's Cancer Registry. The first two digits specify the year of diagnosis. The last four numbers are the numeric order in which the case was entered into the database.

Adjusted (observed) survival rate: Whenever reliable information on cause of death is available, an adjustment can be made for deaths due to causes other than the disease under study. Patients who died without disease are treated in the same manner as patients "last seen alive during the year."

AJCC stage: A staging system developed by the American Joint Committee on Cancer and the International Union Against Cancer. It takes into account the tumor size (T) and/or depth of invasion, lymph node involvement (N) and distant metastases (M). A combination of T, N and M elements gives an overall classification of stage 0, I, II, III, IV or unknown stage.

**Analytic case:** A case that is first diagnosed and/or receives all or part of the first course of treatment at The University of Kansas Cancer Center.

**Distant:** A malignant neoplasm that has spread to parts of the body remote from the primary tumor either by direct extension or by discontinuous metastasis to other organs, tissues or lymph nodes.

**In situ:** A neoplasm that fulfills all microscopic criteria for malignancy without invasion.

**Localized:** A locally staged neoplasm that is restricted to the organ of origin.

**Nonanalytic case:** A case that was diagnosed elsewhere and received all the first course of treatment at another institution, presenting here for recurrence or progression of disease.

**Regional:** A neoplasm that has spread by direct extension to immediately adjacent organs or tissues and/or regional lymph nodes.

**Systemic:** A neoplasm that is disseminated throughout the body or found in blood and/or bone marrow.

**Unknown:** A neoplasm whose stage cannot be determined by a medical authority or indeterminate stage from the medical record.

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