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Cancer Care Annual Report 2013-2014

Children's Mercy Hospital

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TRANSFORMING LIVES:

SURVIVE & THRIVE PROGRAM

2013-2014 Cancer Care Annual Report

Children's Mercy
KANSAS CITY

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One of the most rewarding things about a career in health care is seeing the progress we make in treating illness and disease. While the so-called "war on cancer" continues, we know we have many new weapons to help the children who are fighting this struggle.

Yet, as we are more successful in fighting and defeating the scourge of cancer, we must confront new challenges: how do we help the survivors and their families deal with the unique problems they are presented with? That's where our special Survive & Thrive program comes in. It is the focus of this 2014 Cancer Care Annual Report.

Survive & Thrive is designed for the special needs of cancer survivors, and their numbers are thankfully growing! Working with the Midwest Cancer Alliance and the University of Kansas, we help our patients transition their care from Children's Mercy to an adult health-care setting. While transitioning can be difficult, we smooth the path to make it less so.

Please take a few moments to look at what we have accomplished. Take note of 14-year old Emily who, along with her family, received devastating news in 2002 that she had brain cancer. Two surgeries and rounds and rounds of chemotherapy later, Emily has now been cancer free for 10 years and is as gregarious and lively as ever. She is part of Survive & Thrive.

Emily is also the reason we are all here. To make progress. To win the battles. To fight for the children – who are our real bosses!

Sincerely,

Randall O'Donnell

Randall L. O'Donnell, PhD
President and CEO
Children's Mercy

Alan S. Gamis, MD, MPH
Associate Division Director, Division of Hematology/ Oncology/BMT
Chief, Section of Oncology
Professor of Pediatrics, University of Missouri-Kansas City School of Medicine

In this year's annual report of the Children's Mercy Cancer Center, we focus on our patients' long-term outcomes and their quality of life after cancer.

With increasing cure rates, we have ever-increasing numbers of children and young adults who are survivors of childhood cancer. Recent reports, based on SEER data, estimate that 1 out of every 640 young adults between age 20 and 39 are pediatric cancer survivors.

This is a wonderful problem to have, but one which we must face with increased effort to provide these heroes their greatest opportunity for a long and healthy life. That is, we want our childhood cancer survivors to thrive!

Among the variety of programs here, I am pleased to introduce to you our established and expanding Survive & Thrive program. As you will see, this is a comprehensive effort of many health care professionals and medical specialties. As both a clinical service to our current patients and a research program to benefit our future patients, we are committed to reduce sequelae of cancer and its therapy, to overcome those sequelae that do occur, and to assist our children in their transition to adult providers who are up to date on the experiences and the challenges faced by our survivors.

I hope this year's annual report will provide you a better understanding of the challenges these children face and the wonderful program we have to help our patients thrive after their battle with cancer.

Joy M. Fulbright, MD

Director, Survive & Thrive Program

Director, Adolescent and Young Adult Program

Division of Hematology/Oncology/BMT

Assistant Professor of Pediatrics, University of Missouri-Kansas City School of Medicine

Dear Colleagues and Friends,

In the past, our annual report has focused on certain types of cancer.

This year, it is my pleasure to be able to present a topic – survivorship -- that pertains to all of our patients.

Almost 80 percent of children diagnosed with cancer survive! With this increase in survival rates, we have been able to devote more time and effort to learning about issues affecting cancer survivors and improving their quality of life.

The diagnosis and treatment of cancer disrupts a person's normal growth and development. Our goal at Children's Mercy is to provide treatment that minimizes this disruption. We do this with a multidisciplinary approach.

Starting from the time of diagnosis, patients and families meet with a social worker and a nurse practitioner. Emotional and physical support is provided throughout therapy by child life, chaplaincy, psychology, music therapy, physical therapy and occupational therapy. We are able to provide massage therapy and a full-time school teacher thanks to generous community support. I tell my patients that we want them to get smarter during therapy!

We are fortunate to have the resources to continue this multidisciplinary care after patients complete their cancer therapy. Patients who completed therapy at least two years ago and it has been five years since they were diagnosed are followed in the Survive & Thrive Program. The name of the clinic reminds us of its mission, which is to ensure that after survival of cancer, patients thrive and are provided with the tools they need to lead healthy and meaningful lives.

Over the last couple of decades, we have been working toward making cancer therapy less toxic. Unfortunately, many of the more effective cancer therapies can still cause immediate and long-term side effects. This annual report focuses on the services and education we provide for our patients and their families to help identify, prevent and treat late effects.

There are many transitions in a cancer patient's journey: diagnosis and treatment, completion of treatment, transition from the primary oncologist to the Survive & Thrive Program, and finally, leaving Children's Mercy to move into care with an adult provider. One of the main goals in Survive & Thrive is to help facilitate the transition to adult care. We provide resources, facilitate conversations and work with community providers to ensure that this last transition is as smooth as possible.

I hope by reading this year's report you will learn from our survivors the amazing things they are doing with their lives and about the work that goes on at Children's Mercy to help them on their journey.

Thank you for trusting us with the care of these remarkable patients who are your friends, neighbors, patients, and relatives. I feel blessed every day to provide care for them and to work in an organization and community that cares so much.

All the Best,

CANCER REGISTRY

The Cancer Registry at Children's Mercy is a database of all cancer and benign brain tumor patients that are diagnosed or treated here. All heath care facilities are required by federal and state law to report basic information about cancer and benign brain tumors. Without complete and accurate data, it would be difficult to develop effective, comprehensive cancer prevention and control programs.

As we look at survival in this annual report, we are reminded of the need for follow-up with our patients so we can evaluate the best treatment methods and know the outcomes.

The registry staff at Children's Mercy keeps disease status and follow-up information current. This is done by contacting primary care physicians, accessing the patient's Children's Mercy medical record, and directly contacting the parents and patients. All of the registry activities are conducted according to the HIPAA privacy regulations. Please feel free to contact the registry by secure email at cancerregistry@cmh.edu.

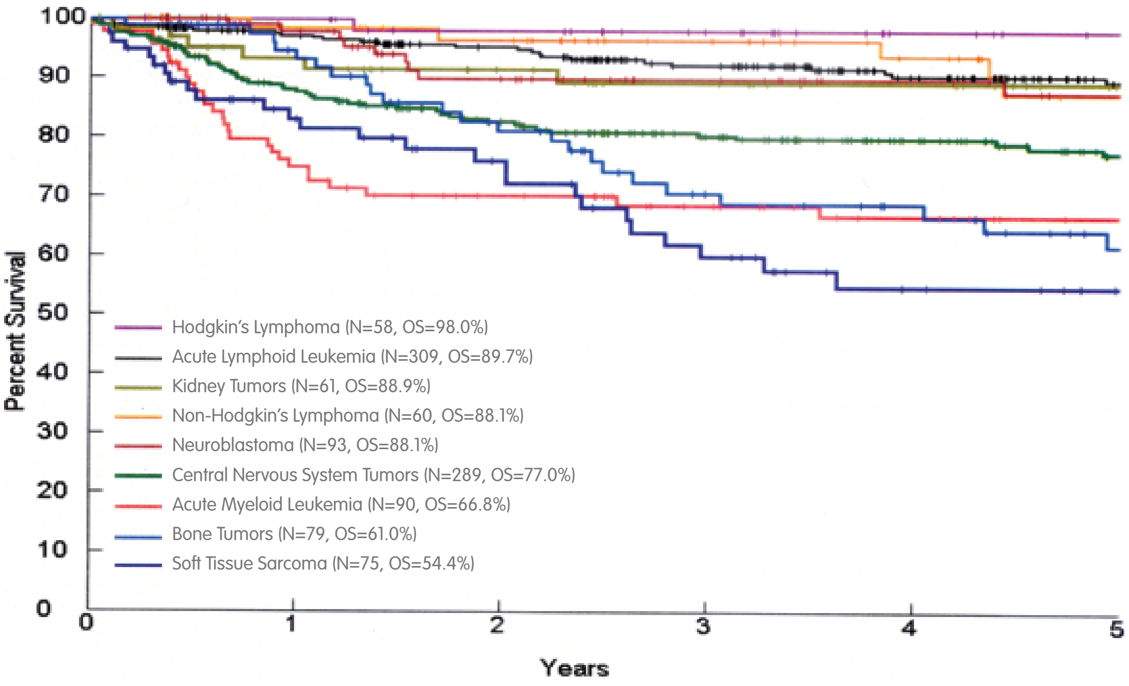
2013 Registry Facts and Figures

- 174 new primary diseases added. (See the frequency table for further breakdown of disease types and percentages.)
- The median age of diagnosis was 9.5 years old.
    - 23 patients were less than 1 year of age when diagnosed
    - 48 patients ages 1-4
    - 33 patients ages 5-9
    - 40 patients ages 10-14
    - 30 patients ages 15-19.
- 88 females and 86 males
- 148 Caucasians (including 21 identified as of Spanish/Hispanic ethnicity)
- 19 African-Americans
- 7 designated as "other" race.

Five-Year Relative Survival-National Comparison Patients Diagnosed from 2004 to 2010 Children's Mercy Kansas City Versus Surveillance Epidemiology and End Results (SEER)

DIAGNOSIS	CMKC	SEER
Acute Lymphoid Leukemia (ALL)	90.4%	87.2%
Acute Myeloid Leukemia (AML)	67.8%	62.3%
Hodgkin's Lymphoma	97.6%	96.4%
Non Hodgkin's Lymphoma	89.1%	86.5%
CNS (Central Nervous System)	78.8%	73.2%
Wilms' Tumor and other Non-epithelieal Renal Tumors	85.5%	89.7%
Neuroblastoma and Ganglioneuroblastoma	85.4%	78.4%
Malignant Bone Tumors	61.6%	69.5%
Soft Tissue and Other Extraosseous Sarcomas	61.9%	71.3%
Malignant Gonadal Germ Cell	86.1%	95.7%

Five-Year Overall Survival - Patients Diagnosed from 2004 to 2013



Frequency of Diagnosis 2013

Diagnosis	Totals	Percentage
Central Nervous System	**54**	**31**
Astrocytoma	10	
Glioma	12	
Medulloblastoma	3	
Ependymoma	3	
Atypical Teratoid Rhabdoid	3	
Gliobastoma Multiforme	5	
Pineal Parenchymal Tumor	1	
Gliomatosis cerebri	1	
Germ Cell of CNS	3	
Benign Borderline CNS	13	
Leukemia	**39**	**23**
ALL	32	
AML	7	
Lymphoma	**13**	**7**
Non-Hodgkin's	7	
Hodgkin's	6	
Neuroblastoma	**10**	**6**
Bone Tumors	**9**	**5**
Osteosarcoma	3	
Ewings	6	
Kidney Tumors	**3**	**2**
Wilms'	2	
Renal Cell Carcinoma	1	
Langerhan's Cell Histiocytosis	**7**	**4**
Germ Cell Tumor	**7**	**4**
Rhabdomyosarcoma	**5**	**3**
Retinoblastoma	**3**	**2**
Other Malignant	**13**	**7**
Myelodysplastic Snydrome	**1**	
Hepatoblastoma	**1**	
Malignant Rhaboid Tumor	**1**	
Non- Rhabdo. Soft Tissue Sarcoma's	**5**	
Desmoplastic Small Round Cell	1	
Infantile Fibrosarcoma	1	
Synovial Sarcoma	1	
Spindel Cell Sarcoma	1	
Undifferentiated Round Cell	1	
Carcinoma	**5**	
Neuroendocrine Carcinoma	2	
Papillary Carcinoma of Thyroid	1	
Adenocarcinoma	1	
Atypical Carcinoid	1	
Benign Reportable Conditions	**11**	**6**
Teratoma	7	
TMD/TAM- Transient Myeloproliferative Disorder / Transient Abnormal Myelopoiesis	2	
Desmoid Tumors	2	
TOTAL	**174**	**100**

OVERVIEW

The Survive & Thrive Program offers comprehensive medical and emotional care to childhood cancer survivors who are at least two years off treatment and five years from the date of diagnosis.

The comprehensive care provided includes education on late effects of cancer treatment and recommendations for maintaining a healthy lifestyle. During a clinic visit, survivors are seen by an oncologist, nurse practitioner, social worker and dietitian. The visit includes a thorough physical exam and recommendations for long-term follow-up care. A nutritional assessment, psychosocial assessment and education are performed during visit based on these recommendations. As survivors get older, preparation for transition to adult providers is incorporated into each clinic visit.

Survivors are at risk for late effects from their cancer and treatment at any point during or after therapy. Late effects of treatment can be physical or emotional and typically appear in the second decade of life. Some late effects resolve while others may become chronic health problems. Late effects may be preventable or modifiable, which is why yearly lifelong follow-up is important for all survivors. The role of the Survive & Thrive Program is to ensure survivors and their families are aware of the potential late effects and to assist with developing a long-term follow-up plan.

The team provides each survivor with a copy of their oncology treatment summary, along with education about potential late effects. A treatment summary is a document that summarizes a survivor's cancer history and includes: diagnosis, age at diagnosis, dates on and off therapy, type of treatment received and doses, surgeries, and any complications or known late effects. With this information, a health care provider can begin to develop a follow-up plan to monitor survivors for late effects of therapy.

In the Survive & Thrive Program treatment summaries are created using the Passport for Care® application. Passport for Care is a secure electronic program developed by Baylor College of Medicine and Texas Children's Cancer Center. Passport for Care links electronically to the Children's Oncology Group (COG) screening guidelines to assemble individualized recommendations for follow-up that are based on a survivor's history. Passport for Care also offers educational resources which help survivors better understand their potential late effects and

how to stay healthy. The team follows the COG Long-term Follow-up Guidelines for Survivors of Childhood, Adolescent and Young Adult Cancers to develop an individualized follow-up plan for each survivor.

Late effects are influenced by multiple factors including diagnosis, treatment, gender, age at treatment, genetics and lifestyle choices, to name a few. Due to the wide variation of late effects, the Survive & Thrive team works closely with providers in other specialties, including endocrinology, developmental and behavioral sciences, cardiology, hearing and speech, pulmonology and the liver care team. Through collaboration, we have built relationships with providers who have an understanding of how cancer therapy can impact a specific body system. Our collaboration with endocrinology has led to having an endocrinologist in the Survive & Thrive Program once a month to see survivors. Combining clinics eliminates an appointment for survivors and their families and allows providers to work together to provide comprehensive care. Another benefit of the combined clinic includes clear plans for transition of care, ensuring all members of the medical team are sharing a clear and consistent plan with survivors.

The graduation from treatment into the Survive & Thrive Program is the beginning of the lifelong follow-up care that is crucial for all childhood cancer survivors. Survive & Thrive ensures that survivors receive the individualized care they need in a multidisciplinary approach. The Survive & Thrive Program allows survivors to see multiple providers in one visit focusing on maintaining and improving health, along with screening for late effects of cancer treatment.

Community Support for Survive & Thrive Program

Community support allows the Survive & Thrive Program an opportunity to provide more than just exceptional patient care. The support received allows the team to provide the most up to date education materials to survivors, engage in research opportunities and develop educational programs for community providers.

Lawrence Rock'n Bowl: The Lawrence (Kan.) Rock'n Bowl aims to provide "a STRIKE in the fight against cancer." With more than two dozen kids from the Lawrence area being treated for cancer at Children's Mercy, the organizers of this annual bowling tournament love hosting area families and supporters for an afternoon at the bowling alley. Since 2013, the event has raised more than $5,000 for Survive & Thrive with plans to continue to grow its support.

Sunflowers to Roses Bike Ride: The annual Sunflowers to Roses Bike Ride invites cyclists to "Join the fight. Enjoy the ride." Taking cyclists through the beautiful scenery of southern Johnson County, Kan., Sunflowers to Roses continues to raise the bar each year, providing funds, awareness and overall support for Survive & Thrive.

JEANETTA DAVIS

Childhood is a time of fond memories for most people. But, for Jeanetta Davis, it's a time that—on a very basic level—she simply endured.

The 17-year-old's earliest recollections center on chronic pain that started around age 2. "My stomach constantly hurt, and I was always throwing up," she remembers. "I'd be walking, and everything would get dark and then disappear."

When her mother took her to the doctor for a check-up at age 2½, he delivered a frightening diagnosis: stage-four neuroblastoma.

It was only the beginning of Jeanetta's dark childhood memories.

A Steadfast Source of Support

By age six, Jeanetta was no longer in her mother's care. Over the next 10 years, she moved through a series of foster homes. But while the individuals overseeing her day-to-day care rotated in and out of her life, one constant stood firm and welcoming: the staff at Children's Mercy Hospital.

"As a small child, I loved Children's Mercy," Jeanetta recalls. "All of my nurses and doctors were so helpful and nice. They made the whole experience a lot less scary. I still love going there."

Jeanetta says that, while the treatment she received at Children's Mercy saved her life, it was the people who truly impacted her. "The personal connections and personal relationships I developed with the staff helped me stay positive about my diagnosis," she explains. "There was always someone there to cheer me up or accommodate me to the best of their ability."

Since her diagnosis as a toddler, Jeanetta has been under the care of the dedicated staff working in Children's Mercy's Oncology Department. Treatments have included radiation, chemotherapy and surgery. While many might consider the latter to be among the memories a child might try to forget, for Jeanetta, her surgeries were a fortunate aspect of her experience.

"My doctors always made sure I had whatever toys I wanted before my surgeries," she says with fondness. "They picked out movies for me to watch to get me in a good mood. Afterward, they pampered me with snacks and Sprite. I loved that I got to rest peacefully after each of my surgeries or a day of tests. I was always so tired."

A Future Focused on Others

Today, Jeanetta lives in Kansas City, Kan., with foster parents LeeAnn and Mike French. Jeanetta arrived at her current home on her 16th birthday, and no gift could have been sweeter to a young woman who had endured so much.

"She's been a huge blessing in my life," Jeanetta says of LeeAnn, "not just regarding taking care of my medical needs but as an overall parent. She's always taking me to my appointments and trying to keep me well."

That loving care has been important because, while she's been in remission since she was 5, Jeanetta's health has never been like other children's. "I couldn't always play and run around like the other little kids," she explains. "I've always had many doctor's appointments and check-ups to deal with. Since middle school, my health has been better. But I get severe sinus infections because my immune system is compromised and very weak." Jeanetta's cancer also caused her to develop hypothyroidism, a health concern she'll have to manage for the rest of her life.

Such issues are common among child survivors of cancer, who can face a variety of health issues as they mature. Referred to as late effects, such issues often don't show up for two to five years after treatment—and often even later.

Jeanetta with mom LeeAnn

Helping Survivors Thrive

To support children like Jeanetta, who just turned 18 in December, Children's Mercy created the Survive & Thrive Program. The program helps childhood cancer survivors and their families understand the potential late effects that can occur. It also ensures necessary screenings continue over the ensuing years and helps with the transition of medical care to adult providers.

"By utilizing a treatment summary, we can make sure Jeanetta receives all the recommended screenings to detect late effects early, such as echocardiograms to detect heart dysfunction," says Joy M. Fulbright, MD, Director of the Survive & Thrive Program. "We'll provide Jeanetta with the education she needs to be aware of changes in her body to bring to the attention of a health care worker."

Dr. Fulbright says the program will also empower Jeanetta to lead a healthy lifestyle by providing nutritional support—another key to helping the young woman remain healthy in years to come.

Jeanetta says such forward-thinking care is just another example of what makes Children's Mercy so commendable. "Children's Mercy definitely is a technologically advanced hospital and is one of the best hospitals for children with cancer," she says.

That care was so impactful that it has influenced Jeanetta's career plans. "From the positive experiences I had at the hospital," she explains, "I knew I wanted to help others and return the favor." Thus, she's set her sights on being an attorney so she can aid other children in foster care.

Joy Fulbright, MD

LeeAnn hopes others recognize what a caring place Children's Mercy is. She says, "They really make you feel everything will be ok."

SECONDARY MALIGNANICES


Alan Gamis, MD

Many cancer survivors are at an increased risk of developing another cancer because of the therapy they received to treat their primary cancer. Cancers that develop due to cancer treatment are classified as secondary malignancies (SMNs).

The treatment for most types of cancer includes radiation therapy and/or chemotherapy. Traditional chemotherapy targets fast-growing cells by interrupting the process of cell/division and growth. It does this by interfering with the copying of DNA. Unfortunately, cancer cells are not the only cells in the body which are growing fast, so damage to the DNA of healthy cells also can occur. Radiation targets the DNA of the cells in the area of the radiation field. This DNA damage places patients at risk for developing another cancer. Patients with specific genetic mutations may be at an even higher risk of developing a SMN or another primary malignancy.

The type of SMN a patient is at risk for depends on many factors, including the dose and type of chemotherapy, dose and location of radiation therapy, underlying genetics, and environmental exposures. Having a treatment summary is essential in helping determine the risks a cancer survivor has for developing a SMN. In our Survive & Thrive Program, we review a patient's treatment summary and discuss a patient's risk factors for developing a SMN. We monitor patients for these SMNs and also give guidance to the patients and their families regarding signs and symptoms of a secondary cancer.

The incidence and type of SMNs diagnosed between Jan. 1, 1995 and Dec. 31, 2013 in patients previously treated for cancer at Children's Mercy are listed in Table 1. Incidence of SMNs in our patient population during this time period was 1.4 percent. The Childhood Cancer Survivor Study (CCSS) is a study of a cohort of patients that were diagnosed with primary cancer under age 21 between Jan. 1, 1970 and Dec. 31, 1986, and survived at least five years after initial diagnosis. The CCSS reported incidence of 3.2 percent of SMNs (excluding non-melanoma skin cancers-NMSCs) when they evaluated this cohort in 2000.[1]

The CCSS continued to follow the same cohort of patients and as of Jan. 1, 2006 reported a cumulative incidence of SMNs increased to 9.3 percent. This emphasizes the importance of patients being followed long-term for the risk of developing SMNs. In the Children's Mercy cohort the most commonly reported SMN was leukemia where in the CCSS cohort leukemia is the sixth most common diagnosis. Breast cancer and thyroid cancer are the two most common. The difference in secondary malignancy types and incidence is likely due to the time from therapy patients were followed and change in therapy from the time from the CCSS patients were treated to when our patients were treated. The majority of the patients in the Children's Mercy cohort were diagnosed with primary cancer after 1990.

A major emphasis in the Survive & Thrive Program is prevention of SMNs. Skin cancer is one of the secondary malignancies that we can help reduce the risk of developing. We review the importance of sun safety and distribute age-appropriate literature that reviews what changes in a mole are concerning, how to perform self-skin checks and sun safety at patient's yearly visits. Importance of avoidance of tobacco products is discussed starting at a young age.

Another part of prevention is performing and obtaining screening exams per national recommendations. For some of our patients, these exams need to occur earlier than the general population due to their cancer therapy. For example, females who have received chest radiation may need to receive breast exams as early as age 25 due to their increased risk for breast cancer.

Children's Mercy Secondary Malignancies

Definition: A second malignancy, also known as a subsequent primary, is any distinct cancer diagnosed after the first one and not related to it. A patient with more than one primary is said to have multiple primaries.

Total Patients with Malignancies Diagnosed - 1995-2013 = 2,154

SECONDARY MALIGNANCIES – 31 – 1.4%

Table 1

SECONDARY MALIGNANCY	NUMBER	PERCENT
Myeloid Leukemia	8	25.8
Osteosarcoma	6	19.4
CNS	4	13.0
Myelodysplastic Syndrome	4	13.0
Lymphoma	2	6.4
Melanoma	2	6.4
Thyroid Carcinoma	2	6.4
Gastrointestinal Stromal Tumor (GIST)	1	3.2
Peripheral Nerve Sheath Tumor	1	3.2
Renal Cell Carcinoma	1	3.2

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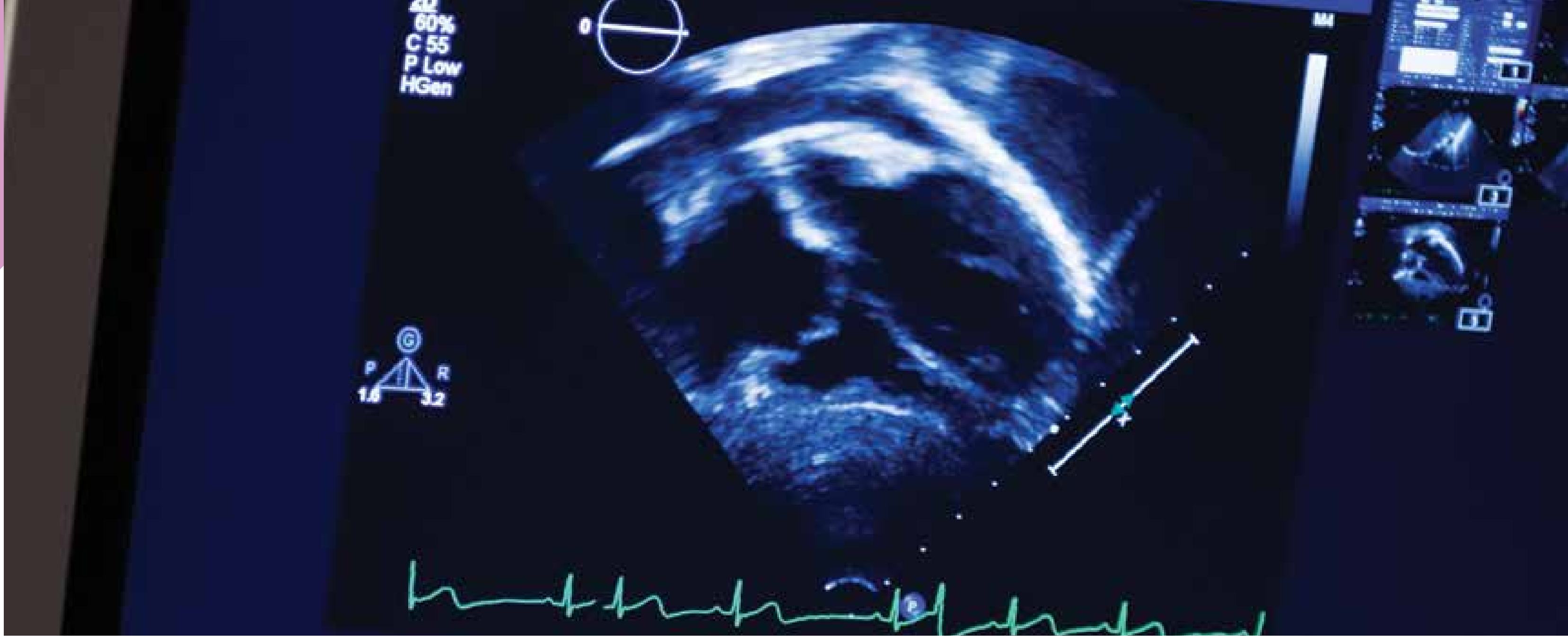
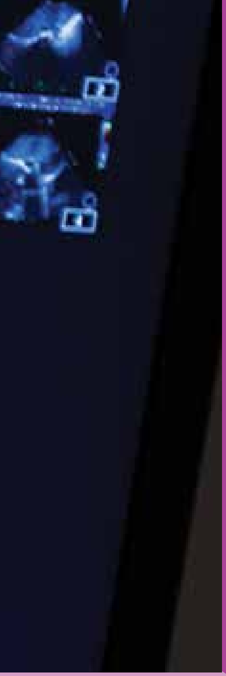
[1] Meadows AT, Friedman DL, Neglia JP, et al. Second neoplasms in survivors of childhood cancer: findings from the Childhood Cancer Survivor Study cohort. *J Clin Oncol.* May 10 2009;27(14):2356-2362.

CARDIOLOGY



Monitoring cardiac health is critical during and after treatment for cancer. Before chemotherapy or stem cell transplant, an electrocardiogram and echocardiogram are routinely performed for baseline cardiac health assessment. Sometimes, there is decline in cardiac function in the initial stages of cancer treatment. A cardiologist can work with the oncologist to improve/stabilize or prevent further decline in cardiac function in these children. More commonly, there is a slow decline in cardiac function over years or decades after cancer treatment. Thanks to previous long-term studies, we know that about 15 percent of kids will develop heart failure over a period of 30 years. Additionally, 10 percent of them will develop strokes in that time period. The latest, 2013 guidelines of the Children's Oncology Group recommends echocardiogram surveillance of cardiac function every one, two or five years depending on the nature and intensity of the cancer treatment and likelihood of cardiac dysfunction.

Cardiology also works closely with the Survive & Thrive Program to monitor for late effects of cancer therapy and promotes a healthy lifestyle to prevent development of late effects. Depending on the findings on the surveillance echocardiogram, we recommend a clinical evaluation and medical management. We are working on newer and more advanced methods like 3-D echocardiography, cardiac MRI and cardiac biomarker testing for precise detection of cardiac dysfunction or cardiac health for cancer survivors. We routinely participate in local community events aimed at improving education and awareness about cardiovascular health, either directly in face-to-face meetings or also using webinars for a much broader audience. Our future endeavors will be aimed at improving and maintaining cardiovascular fitness and endurance of cancer survivors. We are thankful for charitable foundations like Tom Keaveny Foundation for cancer research to improve cardiac care of cancer survivors through generous research funding. Most importantly, we are routinely inspired by the amazing resilience and character of our pediatric cancer survivors.



HEARING & SPEECH

Pediatric audiologists are active members of the multidisciplinary team caring for Survive & Thrive patients. Pediatric audiologists hold doctorate and/or master's degrees in hearing process and pathology and are nationally certified through the American Speech-Language Association. Our nineteen pediatric audiologists at six sites use various behavioral and electrophysiologic test procedures to monitor hearing acuity, evaluate changes in hearing sensitivity, and provide hearing aid services as needed.

Some of the young people seen in Survive & Thrive already have experienced hearing loss secondary to radiation and/or chemotherapies. Hearing loss in this population typically begins in high frequencies affecting understanding of speech especially in the presence of background noise. Some survivors already are hearing aid users and some may become hearing aid users over time. The audiologist's role is to assess hearing and address any changes in hearing sensitivity over time. Speech understanding measures are also used to determine how the loss is affecting the patients understanding and the need for amplification to assist these patients. With the Survive & Thrive Program, audiologists are able to continue to see these cancer survivors after completion of treatment through their twenty-first birthday.

When patients become candidates for amplification, the audiologist provides them with a 'hands on' opportunity to explore amplification solutions that will work best for them in their own unique situation. During this consultation, patients and families learn more about their hearing loss and the benefits and limitations of different types of aids.

Education is a major role for the audiologists with these patients. Patients who have undergone chemotherapy may experience worsening of an already present loss and/or delayed onset hearing loss secondary to their past treatments. Additionally, like the rest of us, their hearing will also be affected by the aging process and exposure to toxic agents in the environment, including noise. Aging and noise have an additive effect on an already present hearing loss. Hearing conservation is of the utmost importance. Audiologists counsel patients about the importance of hearing health, listening to music at appropriate volumes, decreasing amount of time listening to loud music, and wearing ear protection in noisy environments are among the topics discussed.

As these young adults approach age 21, the audiologist works with patients and families on transition of care assisting them in finding adult audiology services in their communities. It is a great feeling to see these patients 'survive and thrive' and go out into our community as young adults.

TONY MANCILLA

As he began developing health issues as a child, Tony Mancilla learned to become very resourceful.

"I was about 8 years old, or 9, when my eyesight started going bad," he says. "I noticed I wasn't seeing as well as I used to. And, then, it got really hard for me to know where I was going and to see who was who."

Not one to let his deteriorating eye sight interfere with his life, Tony learned how to accommodate his growing disability. "Once I recognized voices," he matter-of-factly explains, "I knew who I was talking to."

Diagnosed with neurofibromatosis, a genetic disorder of the nervous system, Tony was treated with radiation under the guidance of Children's Mercy Hospital to eliminate the tumors that were pressing on his optic nerve and causing his blindness. That treatment eventually gave him back some of his vision. In the meantime, the Kansas City, Kan., resident developed additional techniques to help him identify those around him.

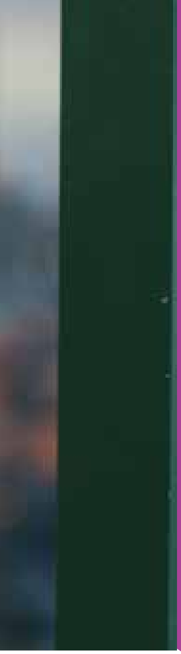
"I created a method of knowing who was who. It was either by the scent of their skin or the perfume or cologne they were wearing," he says. "That's what I would use to determine who was who even before they would speak to me."

In the early years of Tony's treatment, his health journey was managed by the pediatric medical experts at Children's Mercy Hospital. As he matured, he transitioned to the hospital's Survive & Thrive Program.

"I am so happy and very grateful that Children's Mercy Hospital exists," Tony says. "If it weren't for their help, I would not be the person I am today, and I am very appreciative of that."

Last March, Tony turned 21, a milestone in his care journey. As an adult, he was ready for a new support network – one that would further encourage the resourcefulness he exhibited as a boy: the University of Kansas Cancer Center Survivorship Transition Clinic, a joint effort with Children's Mercy and the Midwest Cancer Alliance.

Kyla Alsman, RN, BSN, a "nurse navigator" at the clinic, says the program provides Tony with a contact person to help him navigate his way through the adult hospital setting. "Transition is very hard for individuals," she explains, "especially ones who have a significant health history like Tony."



Becky Lowry, MD, Tony's new primary care physician at the clinic, says such individuals are particularly in need of monitoring and education about the previously mentioned late effects—conditions related to their prior illness and treatment that can manifest years later. The clinic helps with this care by developing a plan that is specific to each individual patient's history.

"While guidelines exist for late effects monitoring," she says, "they are 200 pages long and require a thorough treatment summary for providers to utilize them correctly. We know from the literature that most internal-medicine physicians prefer treating patients like Tony in collaboration with a survivorship/long-term follow-up clinic. Our survivorship clinic provides this focused late-effects monitoring and education for patients like Tony."

The clinic provides an adult setting that assists with navigating further subspecialty care that patients may require in adulthood. "Nationally, most survivorship clinics for patients with a history of childhood cancer are based out of children's hospitals or pediatric clinics," Dr. Lowry explains. "Ours is one of a handful of adult-based survivorship clinics dedicated to these patients. We are so fortunate to have providers who are dedicated to the collaboration efforts between Children's Mercy and the University of Kansas Medical Center, as this is such an important service for patients.

"Pediatric providers and adult providers do not necessarily interface regularly. So, when patients graduate from pediatric care and inquire about adult primary and subspecialty providers, it can be difficult for pediatric physicians to guide them," she adds.

Dr. Lowry says that the biggest challenge for new patients is simply anticipating the first appointment. "Some patients describe anxiety even when seeing one of their primary doctor's partners for urgent-care visits, such as a sinus infection," she says. "As you can imagine, making a move from a pediatric facility and team of providers who has cared for you during what was likely a very stressful time in your life to a new adult facility and new team of providers can be, frankly, frightening." Dr. Lowry, then, says it's been rewarding to see patients' relief when they realize their new care team is already familiar with their history and follow-up needs.

"Now that I'm going to the KU Hospital," Tony explains, "it's a new step for me in my life, because I have to be reliable and responsible for my own appointments."

He adds, "I like the hospital, because they are helping me out—because they are making sure that I'm okay.

"At the time when I was at Children's Mercy Hospital," he adds, "I enjoyed it and appreciated the help that was given to me. I feel so lucky and so blessed to have received their help, and I am very thankful."

Kyla Alsman, RN, BSN

Tony and his mom, Delia

ENDOCRINOLOGY

Sripriya Raman, MD

It is estimated that about one in every 640 young adults living in the United States is a childhood cancer survivor. Studies show that 40 percent of all childhood cancer survivors will have one or more endocrine disorders in their lifetime. Endocrine late effects from prior cancer treatments (growth hormone deficiency, thyroid, gonadal or adrenal dysfunction, obesity, poor bone health) are among the most common complications in childhood cancer survivors. Patients exposed to high doses of alkylating agents and radiation therapy are particularly at high risk for developing endocrinopathies (e.g. survivors of CNS tumors, hematopoietic stem cell transplant and Hodgkin's lymphoma).

The Endocrine Disorders In Cancer Survivors (EDICS) Clinic focuses on providing comprehensive endocrine care to the cancer survivors referred from Survive & Thrive Program and other oncology services. In addition to receiving hormone replacement therapy, patients are educated on their medical condition and possible future endocrine problems based on their individual cancer treatements. EDICS team providers are Julia Broussard, MD, and Sripriya Raman, MD. EDICS Clinic makes Children's Mercy one of the few places in the country with a subspecialty clinic focused on endocrinopathies in childhood cancer survivors.

The EDICS Clinic team works closely with the Survive & Thrive team to coordinate patients' medical care, accommodate survivors' needs and make it easier for them to attend Children's Mercy appointments. That is why the Endocrine and Survive & Thrive (EaST) Clinic was created. EaST Clinic is a monthy multidisciplinary clinic. During this clinic, patients and their families are seen by oncology, endocrine, nutrition and social work, with

laboratory/imaging services coordinated to take place on the same day. This collaboration leads to a decrease in time away from school/work for patients and their families and enhances the clinical and research opportunities for both teams.

October 2013 marked the beginning of the quarterly EDICS Transition Clinic. Also, in order to improve access to our services for patients who live far away, the EDICS Telemedicine Clinic will start in July 2014 in St. Joseph, Mo. and expanded its services to Joplin, Mo.

The successful collaboration between the EDICS and Survive & Thrive team has resulted in improved patient care and increased family satisfaction with the medical care at Children's Mercy.

Julia Broussard, MD

SOCIAL WORK


Amanda Trout, MSW, LCSW

During a visit to the Survive & Thrive Program, the social worker completes a yearly comprehensive psychosocial assessment of each patient and family as recommended by the COG Long-Term Follow-up Guidelines.

While many pediatric cancer survivors adjust well throughout life, some experience psychosocial late effects from treatment. Cancer treatments can affect educational progress during treatment due to absences and low energy levels. Additionally, some treatments that target the central nervous system (brain and/or spinal cord) may affect memory and learning abilities, which can affect educational or vocational progress long term. Pediatric cancer survivors can also struggle with emotional issues, such as anxiety, depression, post-traumatic stress, and social withdrawal. Financial stressors, such as access to health insurance, may also be present. For adolescent and young adult pediatric cancer survivors, transition to adult care can be particularly stressful. A social worker can assist with identifying and addressing barriers related to transition and provide support through this process.

Based on risk factors identified during the assessment process, patients and families are provided with referrals to appropriate professionals or community agencies for further evaluation and support services. Supportive counseling can also be provided during the clinic appointment itself, and the social worker is available as needed to provide ongoing psychosocial support.

PSYCHOLOGY

The Children's Mercy Survive & Thrive Program is a multidisciplinary team that serves pediatric survivors of cancer. Our goal is to evaluate and monitor patients for potential developmental late effects that can result from cancer treatments. Based on presenting needs or concerns, referrals are made to appropriate specialists. The role of a clinical psychologist within the Survive & Thrive Program, is available for both individual and family therapy services and neuropsychological testing for cancer survivors.

It is not uncommon for patients to experience lingering physical, psychological and interpersonal challenges. While many cancer survivors adapt in overall healthy ways, many struggle with symptoms of depression, anxiety and post-traumatic stress. Many patients may also experience worry, guilt, concerns about body image, communication difficulties with family members and peers, feelings of losing control, sadness and confusion or fear about recurrence that cause significant distress or disruption to their daily lives. For these patients, individual cognitive-behavioral therapy can be effective. This psychological intervention focuses on identifying and correcting dysfunctional thoughts and incorporates relaxation techniques and problem-solving skills, a combination that works to reduce distress and improve adjustment.

It is estimated that about 40 percent of pediatric and adult cancer survivors experience impairments in their cognitive abilities (e.g., difficulties with attention and concentration, short-term memory, processing and organizing complex information). Because of this, Survive & Thrive provides annual evaluations for cancer survivors which allow us to monitor changes, identify any new concerns and connect patients with the appropriate resources and services. When needed, some patients may be referred for neuropsychological testing, which involves a variety of activities that allow us to observe how a child or adolescent processes and responds to different kinds of information. Based on the results of this detailed testing, families are provided with (1) an understanding of how treatment has affected thinking, learning and behavior, (2) a picture of the patient's strengths and weaknesses, (3) identification of what services and accommodations may be needed in the educational or vocational setting and (4) any necessary referrals for cognitive behavioral therapy.

Lisa Peters, LMSW, LCSW

EMILY CONNOR

When intense stomachaches made 21-month-old Emily Connor of Liberty, Mo., unusually lethargic and weak, her parents, Scott and Denise Connor, were told not to worry. She had the flu.

But after 14 days of doctor visits, antibiotics and no improvement, Emily was taken to the Emergency Department at Children's Mercy Hospital.

"Emily was outgoing from the day she was born," Denise said. "But we noticed she was acting very different—quiet and upset. We knew something was wrong."

Discovering the Problem

Initially, the doctors at Children's Mercy believed Emily likely had a stomach virus. Parental instinct made Scott and Denise insist that something else be considered.

"At this point, we knew whatever was wrong had to be serious because when she tried to smile, half of her mouth drooped just a little bit. It was almost unnoticeable, but it was there," Scott recalled. "So, we looked at the doctors and said, 'We have five other children and we aren't overly paranoid parents. We truly believe something is seriously wrong. Please figure something else out, because we aren't leaving.'"

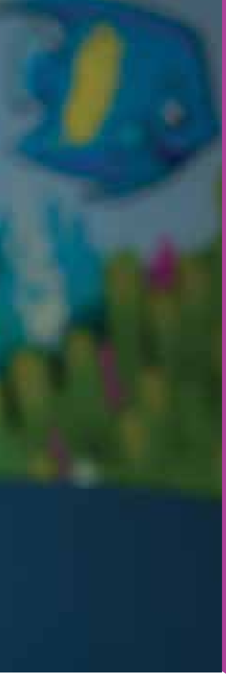
Emily underwent a CT scan. The test results would change Emily's and the family's lives forever.

Receiving the News

"I just remember a brigade of people in white coats coming into the room to give us an update," said Denise. "We knew as soon as they opened the doors and we saw all those people that it probably wasn't good news."

On March 17, 2002, exactly 21 months from the day of Emily's birth, the Connor family was faced with devastating news: Emily had brain cancer.

"Emily had an Atypical Teratoid / Rhabdoid Tumor (ATRT) of the brain that was more than seven centimeters in diameter and had wrapped itself around a major artery," describes Maxine Hetherington, MD, the pediatric oncologist who oversaw her care. "ATRTs are very rare, high-grade tumors that occur most often in children under the age of 3."



ATRTs are also extremely aggressive, making the survival rate for children diagnosed before the age of 3 less than 10 percent. Being only 21 months old, Emily's situation seemed grim.

Wendy McClellan, RN, MSN, CPNP

Treatment

A few days later, Emily underwent surgery with Gregory Hornig, MD, Neurosurgery Section Chief at Children's Mercy. After a five-hour operation, more than 90 percent of the tumor was removed.

Following surgery, Emily received six rounds of chemotherapy. The latter half of her chemotherapy treatments were combined with a procedure called stem cell rescue. This allows stem cells to be taken from Emily's body and then put back immediately following these high-dose chemotherapy sessions. In the fall of 2002, Emily underwent six weeks of intensity-modified radiation therapy to try and kill any remaining tumor.

Emily with dad Scott

Just when the Connor family thought they were through the treatment process, an MRI in early 2003 showed the tumor had returned. Having exhausted their chemotherapy options, Emily underwent gamma knife surgery, again with Dr. Hornig, to irradiate the tumor bed. Shortly after, she began blood brain barrier disruption" treatments monthly until February 2004. In June of that year, Emily received an "all clear" MRI that would put her on the road to being cancer-free. Regular checkups with the team at Children's Mercy continue to this day.

Ten Years Strong

Now 14, Emily is as gregarious and lively as ever. She is a patient of the Children's Mercy Survive & Thrive Program, which provides specialized services for cancer survivors. Emily's parents, who never let Emily stay in the hospital without one of them present, say Emily has always been a fighter. Despite a number of side effects from her prior cancer and treatments, Scott says she has the most positive outlook on life of anyone he knows.

"She is an inspiration to everyone who meets her," says Scott.

"Effects of childhood cancer can develop as late as 10 years after treatment, sometimes more," said Wendy McClellan, RN, MSN, CPNP, Survive & Thrive. "Our goal is to make sure survivors and their families get the proper medical and emotional care they need for these sorts of problems."

Summer, 2014 marked the 10-year anniversary that Emily has been cancer-free.

"In some ways it seems like a lifetime ago, and in others it seems like yesterday," said Denise. "You don't realize how special a place like Children's Mercy is until your family needs it. We are truly blessed to have an institution like this in our community. We can never repay the gift that Emily received from Dr. Hetherington, Dr. Gilman, Dr. Hornig, all of her nurses, and the entire staff that continues to oversee her treatment and recovery."

NUTRITION

Sara Jehle, MS, RD, LD

Dietitians perform many roles in the Survive & Thrive Program at Children's Mercy. Patients and families meet one-on-one with a dietitian at their annual Survive & Thrive visit to discuss current dietary habits.

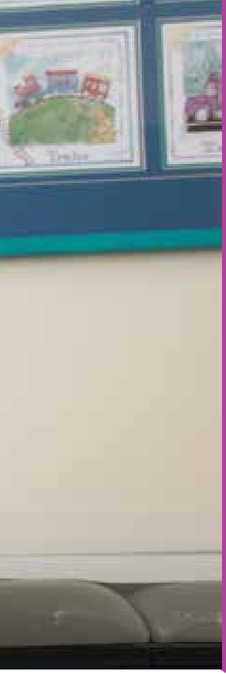
Education is provided to each patient in an effort to help them develop healthy habits to help reduce the risk of chronic disease development. Dietitians also aid in monitoring the potential side effects from chemotherapy, radiation and/or surgery treatments. Potential side effects from treatment that can be influenced by nutrition include growth (weight and height), fat levels in the blood and bone health.

Patients' diets are assessed by the dietitian for nutritional adequacy by discussing what the patient typically eats in a day. Areas of nutritional success and areas where improvement could be warranted are identified. These areas are used as the basis for nutrition goals. Fruits, vegetables, whole grains and calcium intake, along with physical activity guidelines, are examples of healthy lifestyle education provided to patients frequently.

Growth charts are actively monitored to ensure the patient is not gaining too little or too much weight and also show adequate growth in height. If a patient experiences inadequate weight gain, supplements are often recommended. Dietitians also work with these patients to help them identify high-calorie foods that are nutrient dense (i.e. whole-fat dairy, avocados) and can add to their daily intake to promote weight gain. If excess weight gain is experienced, weight management techniques are used focusing on strategies to decrease the intake of sugar-sweetened beverages, decrease the frequency of high-calorie meals/snacks and increase physical activity. Dietitians also assist the medical team in identifying patients who may not be reaching their height potential and discuss with the team if a referral to endocrinology for a growth hormone evaluation would be beneficial.

Blood fat levels such as triglycerides and cholesterol may be elevated in some of the Survive & Thrive patients. Dietitians play a role in monitoring these lab results, providing education to the family on dietary management of elevated levels. For example, triglyceride levels may be lowered by decreasing sugar and fat intake and by weight loss. Bone health can also be compromised in these patients. Dietitians assess calcium and vitamin D intake at each clinic visit. Patients learn about their calcium and vitamin D needs, foods high in calcium and vitamin D and over-the-counter supplements available if intake from food sources is inadequate.

The Survive & Thrive dietitian follows the patients on an annual basis. Additional in-person meetings or telephone calls are also available in an effort to keep the patient on track for a healthy lifestyle.



BRIDGING THE GAP

The need for long-term follow-up care of childhood cancer survivors has been well established and guidelines now exist to help providers monitor for late effects of treatment. However, there continues to be a knowledge gap among health care providers in several topics related to monitoring and early diagnosis of long-term effects. To fill the gap in Fall 2013, we implemented a project titled "Bridging the Gap - Caring for the Adolescent and Adult Survivors of Childhood Cancer." Funding was obtained through the Midwest Cancer Alliance.

The goals of this project were to assess health care providers' knowledge of the unique needs of childhood cancer survivors; develop a face-to-face meeting and web-based educational series to improve that knowledge; and evaluate performance improvement strategies among selected clinical sites. We recruited local, regional and national leaders with experience, talent and a vested interest in provider education and patient management of childhood cancer survivors to lead this project.

A one-day regional educational conference was conducted and attended by 35 physicians, nurses, advanced practice nurses, social workers and allied health professionals. This conference was designed to provide the most current information regarding late effects of treatment and use of the latest COG survivor guidelines. In addition, the workshops provided a forum for networking between primary care providers and subspecialists. We conducted a survey of participants that demonstrated an overall improvement from the pre-conference survey results to the post-conference survey results. The keynote speaker was Tim Folse, MD, who is the Clinical Director for The St. Jude LIFE & After Completion of Therapy Clinics.

In 2014, we are into Phase 2 of the Bridging the Gap project, conducting ongoing webinars. Web conferences are clustered into four sessions focusing on the most common late effects of cancer therapy – endocrine, fertility, cardiac and psychosocial issues. Each session includes topics that cover guidelines for screening and provide reliable, readily obtainable resources that can be used in clinical practice.

Webinar sessions focus on educating health care providers on the late-effects of cancer therapy, current COG guidelines for screening, expert recommendations on how to utilize history and clinical exam to diagnose problems early, and appropriate referral patterns.
The program also provides an opportunity for participants to meet the local experts and build a support network for clinical advice when needed.

TRANSITION


Kyla Alsman, RN, BSN

Transition of care is a gradual process. Preparation begins years before a survivor reaches 21 years of age. In the Survive & Thrive Program, transition is first introduced around 12 years of age and incorporated into each clinic visit until a survivor leaves Children's Mercy. Transition preparation requires more than just establishing care with adult providers. Many survivors were very young when they were treated or may not recall details of their treatment.

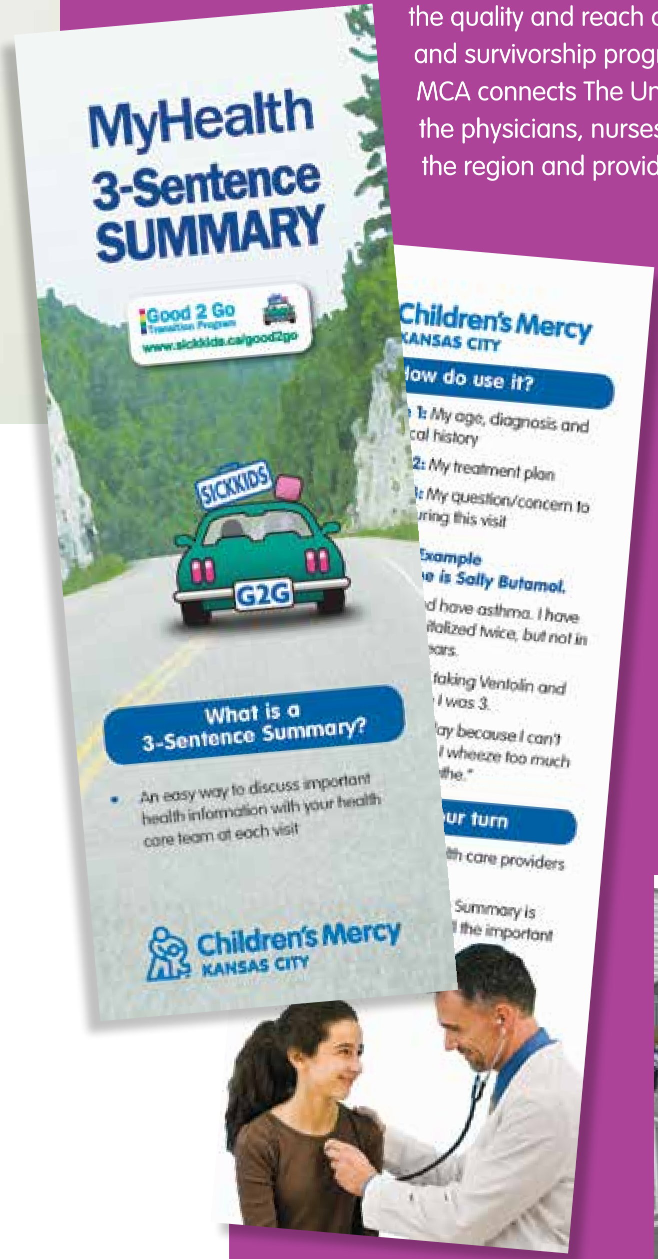
In the Survive & Thrive Program, survivors are encouraged to learn about their history and be able to share their history with medical providers. A developmentally appropriate transition readiness screening tool is used to facilitate a conversation with survivors during clinic visits. This tool allows the team to assess a survivor's knowledge of their medical history, current problems, risks and progress toward transition. The transition readiness screener is first introduced when planning for transition of care first begins. The goal is for survivors to feel comfortable discussing their history and risks with future health care providers and encourage independence. Transition is an individualized process that may occur at different times for each survivor. Along with the transition readiness screener, a three-sentence summary is utilized to guide survivors in communicating their medical history in a concise manner. Transition preparation promotes autonomy, responsibility and self-reliance. Our goal is to empower our survivors to take charge of their health so they can advocate for themselves as they transition to the adult world.

University of Kansas Cancer Center Survivorship Transition Clinic

A long-term collaboration with Midwest Cancer Alliance (MCA), the outreach arm of The University of Kansas Cancer Center (KUCC), and Children's Mercy has resulted in the launch of the Survivorship Transition Clinic at the University of Kansas Medical Center. The Survivorship Transition Clinic is one of the few clinics in the nation that represents collaboration between a free-standing children's hospital and an adult hospital. The clinic is designed to meet the ongoing and unique health care needs of adolescent and young adult survivors who are ready to transition to an adult setting.

MCA is a membership-based organization bringing cancer research, clinical and support professionals together to advance the quality and reach of cancer prevention, early detection, care and survivorship programs across Kansas and western Missouri. MCA connects The University of Kansas Cancer Center with the physicians, nurses and patients battling cancer throughout the region and provide access to cutting-edge clinical trials for patients as close to home as possible. The MCA organization includes the Partners Advisory Board and the Clinical Trials Network.

The MCA Partners Advisory Board is a partnership among KUCC and major regional hospitals and research institutions. The purpose of the board is to maintain National Cancer Institute designation and advance the pursuit of Comprehensive Cancer Center designation for the region by demonstrating collaboration in the areas of research and education and providing annual financial support.



MyHealth
3-Sentence
SUMMARY

Good 2 Go
Transition Program
www.sickkids.ca/good2go

What is a 3-Sentence Summary?

- An easy way to discuss important health information with your health care team at each visit

Children's Mercy
KANSAS CITY

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ow do use it?

1: My age, diagnosis and
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2: My treatment plan
: My question/concern to
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Summary is
the important

Community Support for KUCC Survivorship Transition Clinic

Tour de BBQ Bike Ride:

Known as the best-tasting cycling event around, the Tour de BBQ Bike Ride does more than just fill cyclists' bellies with good BBQ. Since 2012, this popular event has raised more than $150,000 to support a nurse navigator position for the Survivorship Transition Clinic, which helps survivors transition successfully from pediatric to adult care.

de TOUR BBQ

TRANSITION

The collaboration between MCA, KUCC and Children's Mercy allows the transition to be seamless as we address challenges and support the survivors. However, transition of care is not without challenges. For survivors, leaving the familiarity of the pediatric setting can feel overwhelming. Survivors want to know their providers are familiar with their history and future risks. For adult health care providers unfamiliar with pediatric oncology, there is a knowledge gap regarding the needs of survivors and the health risks they face. A nurse navigator works jointly with the Survive & Thrive Program and the Survivorship Transition Clinic at the University of Kansas Medical Center (KUMC). Survivors become acquainted with the nurse navigator prior to leaving the Survive & Thrive Program. The nurse navigator is available to assist survivors as they navigate a new health care system. The Survivorship Transition Clinic allows survivors to see a health care provider who is familiar with the COG survivor guidelines, as well as the unique needs of this population. The collaboration between the Survive & Thrive Program and the Survivorship Transition Clinic allows the nurse navigator and the physician to have additional support when caring for survivors.

The Survivorship Transition Clinic includes a review of the patient's history and treatment, a comprehensive physical, and a psychosocial evaluation. Similar to the Survive & Thrive team, the Survivorship Transition Clinic staff collaborates with multiple specialties to meet the variety of needs of these survivors and make referrals to specialists when necessary. The nurse navigator educates survivors about the most recent recommendations for ongoing follow-up and healthy lifestyle

choices. The goal is to inspire survivors to take charge of their health care in order to minimize their risks.

The collaboration with MCA will increase opportunities to transition survivors to health care providers in their own community. Through MCA, the Survive & Thrive Program team and Survivorship Transition Clinic team will have increased opportunities to provide support, education and resources to providers caring for survivors around the Kansas City metro area and across the state of Kansas. MCA's collaborations with health care providers across the Heartland provide the opportunity in the future to incorporate telemedicine into the Survivorship Transition Clinic. Telemedicine would allow survivors who live miles away to receive the same benefits and care of the Survivorship Transition Clinic in more locations, closer to home and increasing the opportunities to collaborate with health care providers in the communities where survivors live.

Having the Survivorship Transition Clinic at KUMC gives survivors an opportunity to continue to receive care in an environment modeled after the Survive & Thrive Program. The collaboration between Children's Mercy, MCA and KUMC will provide more opportunities for networking, education and research, which are all essential components in ensuring survivors receive the care they need.

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