# OF OMESTER INTEGRITY, COLLABORATION, INNOVATION, GIVING



CookChildren's

FALL 2015

# promise

FAII 2015

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Cook Children's Health Care System
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Cook Children's Health Foundation
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Cook Children's Health Care System is a not-for-profit, nationally recognized pediatric health care organization, comprised of eight entities — Medical Center, Physician Network, Home Health company, Northeast Hospital, Pediatric Surgery Center, Health Plan, Health Services Inc., and Health Foundation.

Cook Children's Medical Center is fully accredited by The Joint Commission and is a member of the Children's Hospital Association, Children's Hospital Association of Texas and Children's Miracle Network Hospitals.

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# Warm regards FROM RICK W. MFRRIII

very day we witness the results of your generosity. Your support is instrumental because it enables us to better serve our patients by providing an array of programs, services and innovative treatments that result in great outcomes and enhance the patient and family experience at Cook Children's. Therefore, their time with us is that much easier, more restorative and leads to a quicker recovery. We see firsthand just how far reaching, life-changing and transformative such breadth of care can be for our patients and their families.

For instance, thanks to donors like you, we opened a state-of-the art MIBG suite; the only one of its kind in the Southwest. Through MIBG, we treat cancer patients with neuroblastoma by providing targeted investigational therapy. And thanks to the design of the suite, unlike other facilities, our parents can stay in a neighboring room to be near their child during their stay and treatment.

At the same time, we continue to collaborate with our peers around the country, including membership in the Children's Oncology Group and New Approaches to Neuroblastoma Therapy consortium. This helps us to remain at the forefront of research, technology and innovative treatments. That collaboration and leading-edge treatment is paying off, helping kids, like Ewing, featured on the cover, win their battle against childhood cancer.

A similar innovative approach is applied to other aspects of care as well. We continue to look for new and novel ways to enhance our environment or improve care, including our Sit...Stay... PLAY program with our service dogs, Ralph and Channel. Because we've seen the therapeutic benefit and healing effect they've had on our patients, we've expanded the program. Ralph and Channel are now joined by golden retrievers Journey and Kitty. It's also why we've added massage and acupuncture therapy services at the medical center. These treatments can

provide important pain relief, promote relaxation, support a patient's emotional well-being and recovery, and, ultimately, aid in the healing process.

Because the month of September is Pediatric Cancer Awareness month, please join with us once again to #erasekidcancer. Last year's campaign was a great success and we hope we can count on your support once again. Because you've shown – generosity heals.

With gratitude,

Rick W. Merrill
President and CEO

Cook Children's Health Care System



# promise

#### ON THE COVER

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- Generosity heals
- A community stands against cancer
- What's new at Cook Children's?



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# Caregiving in action

Leslie Enlow has spent six hours a week for the past eleven years helping kids at COOK CHILDREN'S HEMATOLOGY AND ONCOLOGY CENTER. HER MOTIVATION STEMS FROM LOSING HER OWN DAUGHTER TO ACUTE MYELOID LEUKEMIA IN 2003.



"I do it because I can. It's comfortable for me and I can handle it," said Leslie. "It's a privilege for me to visit with these kids and to play with them."

Her daughter, Alaina, was diagnosed in 2000 at 15 years old. The doctor advised Leslie and her husband John to take their daughter to Cook Children's to receive care. Alaina spent the next two and half years in and out of the hospital, sometimes for months at time.

Alaina loved photography. She shared her work with other patients, staff and families. Several of her photos are displayed throughout the medical center, many of

which she took while traveling with her family to New York and Italy.

In 2001, Alaina successfully underwent a bone marrow transplant. Her older sister Callie was the donor. Alaina was cancer-free for about a year before relapsing and then undergoing a stem cell transplant. Again, her sister Callie was the donor.

Following the successful stem cell transplant, Alaina contracted graft-versus-host disease, a common side effect to a stem cell transplant. Her body was unable to fight it, and in 2003, Alaina unfortunately lost her battle with cancer.

## Caregiving in action

Now, 12 years later, the entire family remains dedicated to helping patients like Alaina in their own battles. Leslie and John are long-time supporters of Cook Children's, and established the Alaina Enlow Fund to help support the Adolescent and Young Adult (AYA) program. They have served on councils and committees to help enhance the patient experience for our families and Leslie has volunteered at Camp Sanguinity, a summer camp for cancer patients and their siblings. Alaina's sister, Callie, is passionate about helping AYA patients, a population that is often overlooked in pediatric health care. And Leslie spends her time with patients and families who need her, even if they don't know they do.

For Leslie, volunteering here was a natural next step in her life. During Alaina's stay, the staff at Cook Children's became like family, and Cook Children's seemed almost like a second home. Leslie normally volunteers in the hematology and oncology outpatient clinic in the Dodson Specialty Clinics building. She plays with kids while they wait to be called back to the see the doctor. Some patients want to play pretend, as if they are the doctor, and they talk very matter-of-factly about procedures and diagnoses. Even as they show her their ports, and tell her "I have cancer," it doesn't faze them. They show incredible strength, and that is what Leslie says inspires her the most.

"I'm just playing a game with them; I don't feel like I am changing lives," Leslie said. "But maybe I am, in some small way."

As a professional guitarist, Leslie brings the gift of music to our patients, too. She played for Alaina when she was sick and it would calm her. Now, she plays for other patients and brings them that same sense of calm. She plays for patients in the critical care units and enjoys watching their heart rates ease down while she plays.

The patients, families and staff have honored Leslie for the impact that she makes. She has received both the Volunteer of the Year and Golden Heart awards in recognition of her extraordinary volunteer efforts.

"I don't do it for the thank-yous, or even the hugs, even though there is nothing better! I do it because I don't want to forget what we went through. Memories fade and you can forget," said Leslie. "I wouldn't trade it. I'm not ready to quit."

And we're not ready for Leslie to quit. She, her husband John and daughters Alaina and Callie are family. We are grateful for their generous hearts and the hope and healing they bring to our families.





Seventh Avenue is a dynamic group of individuals that interact with patients, learn more about pediatric health care and meet other people who share their commitment to Cook Children's.

At Cook Children's, we know that our patients are not alone in their medical journeys. Their families are beside them every day. They are a part of the battles, the triumphs, the hurting and the healing. That's why we created Seventh Avenue in 2010. We saw an opportunity for our community to help our patient families.

Seventh Avenue is a membership organization comprised of individuals, couples and families. This group has formed a wonderful bond and has formed a new kind of family. In just five years, Seventh Avenue has grown to more than 200 members. Members enjoy attending annual kickoff and member events, where they network and learn more about how their generosity makes an impact at Cook Children's.

Membership dues are used to fund various needs across Cook Children's. Those needs are chosen by a committee and based on the grant applications received. In the past, the group has funded projects such as new technology for departments, equipment for families who couldn't otherwise afford it and scholarships to send kids to Cook Children's-sponsored summer camps.

With so many young families in Seventh Avenue, the program is designed with a focus on family philanthropy. Many of the children in the group are Cook Children's patients themselves, and have expressed a desire to help sick kids. Each year, there are several Seventh Avenue events that allow member children to give back directly to the patients through simple service projects or bigger initiatives like the Teddy Bear Picnic (pictured here) and the Warm and Wooly Blanket Drive.

In 2015, Seventh Avenue awarded grants for a total of \$60,220, collected 630 teddy bears to be given to patients, and made 125 blankets. The families at Cook Children's have one more family they can count on – our Seventh Avenue family.

For more information on Seventh Avenue, contact Cook Children's Health Foundation at 682-885-4105.

## A walking miracle

#### Pat Devaney Calls his 11-year-old son, Ewing, a Walking Miracle. And Everyone that knows him agrees.

In July 2011, Ewing was diagnosed with stage 4 neuroblastoma. With the help of his family and friends, and the care he received at Cook Children's, he won his 20-month battle with this rare form of cancer.

Ewing's original treatment plan included a combination of chemotherapy, radiation, a stem cell transplant and antibody therapy. But after testing revealed that cancer still lingered in his bone marrow, and wasn't responding to traditional treatments, his doctor recommended I-131 metaiodobenzylguanidine (MIBG) investigational therapy.

MIBG is a substance that's attached to radioactive iodine. The radioactive iodine is carried to the tumor cells by the MIBG and attaches to them. The radiation damages the cancer cells, shrinking the tumor. Because MIBG is radioactive, it's handled very carefully. It also makes the child radioactive, which means they must stay in a lead-lined room until the radiation has gone down to safe levels.

At the time, this treatment wasn't available at Cook Children's. The closest facility with an MIBG center was in California. The Devaneys spent 10 days there undergoing this targeted therapy, and the long-distance experience offered the family a lot of perspective. Their time in California was short compared to some families who spend months, sometimes years, receiving treatment away from home.

"Continually throughout his treatment, we kept thinking about those people who have to literally uproot their lives to be close to treatment," pondered Traci, Ewing's mom. "I can't imagine what that would be like."

Coincidentally, a few months after the Devaneys returned from MIBG treatment out of state, Cook Children's opened the doors to its own MIBG suite. This donor-funded facility is the only one of its kind in the Southwest, and offers a viewing window, parent-to-child intercom system, and private adjoining room for parents to stay and be close to their child throughout the entire process comforts that weren't available during Ewing's treatment.

"In California, Ewing had a room with a small mirror opposite the door (pictured at right), and we were just able to see him through the reflection in the mirror from our chair in the hallway," said Traci.

The Devaneys talk about how grateful they are to have a leading cancer treatment center right in their backyard. Not only did they have access to excellent care at Cook Children's, but they also could be close to their support system at a time when they needed them the most. Their Cleburne, Texas, community was instrumental in helping them get through those two long

years spent battling neuroblastoma.

A weekly prayer vigil was started by family friends where people from all denominations could band together and pray for Ewing's recovery. Even his elementary school in Cleburne pitched in to host a spaghetti dinner to raise funds for Cook Children's neuroblastoma research program.

From the beginning, Traci and Pat tried their best to remain positive about Ewing's diagnosis. Traci recalls a time when they sat down with staff at Cook Children's.

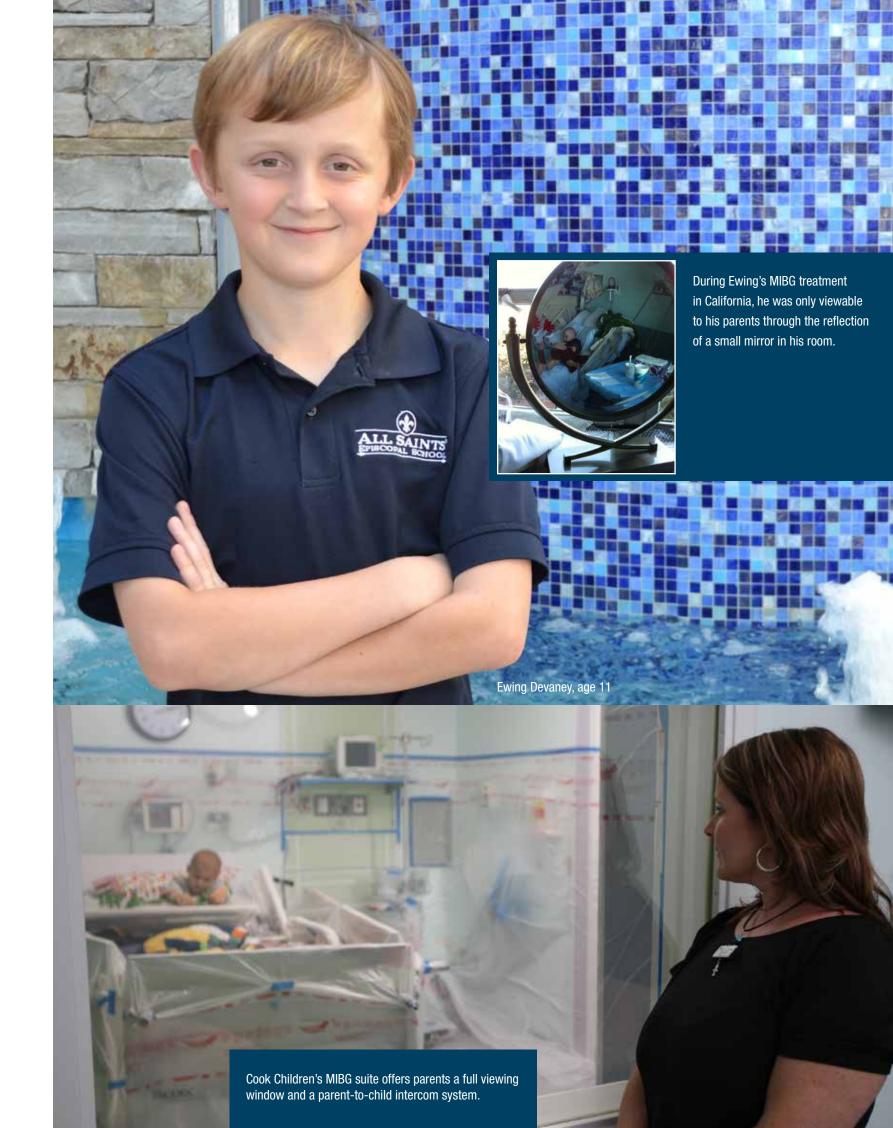
"They asked us, 'Do you want to know the survival rate?' I said, 'No, it doesn't matter.' And I still don't know what the survival rate is. We didn't know where he was going to fall on that scale, so why plant the bad seed to begin with?"

Despite the intensity of this life-altering experience, the Devaneys recognize that their family is blessed beyond measure. The blog they kept throughout this journey is filled with positivity, gratitude and hope for a world without cancer.

One entry reads, "Oddly enough to say, I am thankful for the changes neuroblastoma has made in our lives, as a family, but I'd rather it had not been at my son's expense. We have grown in so many ways individually and as a family. I don't think this would have occurred in our 'normal,' everyday hustle and bustle of having a family, activities and school. You become too wrapped up in these things and society to slow down and see the beauty of life. Once you have lived it, nothing looks the same. I don't want a life where neuroblastoma doesn't exist. I'm so proud of my knowledge of childhood cancer. I want to help make society aware of childhood cancers. I want to give these children a chance to become adults! I want to thank our community, friends and family for not looking away and for becoming aware. I thank God daily for his [Ewing's] supporters — whatever you provide: prayer, support, company, a voice or just hugs. It all makes a huge difference! Being not normal has been a blessing."

Ewing has been cancer-free for two years now. His family knows that although they are doing well now, there is still a war being waged against neuroblastoma. They hope to be able to help keep the conversation going about childhood cancer by sharing their story and reaching out to their community to spread awareness and raise funds for childhood cancer research.

And as for future plans in the fight against neuroblastoma, Pat said, "I think everyone should have to go tour the oncology floor at Cook Children's. I still don't think people understand the degree to what neuroblastoma is and the degree to what these kids go through. One day, we're going to cure it!"



# By the MUINDETS

WHILE THESE NUMBERS ARE IMPRESSIVE, THE PATIENT STORIES BEHIND THEM ARE MORE REMARKABLE. OUR HEROIC PATIENTS AND THEIR FAMILIES INSPIRE US TO CONTINUE IN OUR FIGHT AGAINST PEDIATRIC CANCER.

EVERY MINUTES, SOMEWHERE IN THE WORLD, A PARENT WILL HEAR THE WORDS, "YOUR CHILD HAS CANCER"

CHILDREN WILL
BEAT CANCER

ALL TYPES OF CHILDHOOD CANCERS COMBINED RECEIVE only / percent TOTAL HEMATOLOGY AND ONCOLOGY CENTER PATIENT **ENCOUNTERS AT COOK CHILDREN'S IN 2014** 

FORT WORTH: 10,200

GRAPEVINE: 2,529

MIDLAND: 294

SAN ANGELO: 746
WACO: 126

COOK CHILDREN'S INAUGURAL OUR PROMISE LUNCHEON IN 2015 RAISED MORE THAN \$107.295 TO HELP FUND 180 ACTIVE RESEARCH STUDIES AND 120 THERAPEUTIC TRIALS CURRENTLY TAKING PLACE AT COOK CHILDREN'S

# #erasekidcancer

**Childhood Cancer Awareness Month** September 2014

Facebook impressions: more than 500,000

Twitter impressions: more than 25,000

Donations for research: more than \$44,000

# Ö Ö Ö Ö Ö Ö

## Mark "Hawkeye" Louis

Hawkeye OF NEW COUNTRY 96.3 KSCS IS A VALUED PARTNER OF COOK CHILDREN'S AND CHILDREN'S MIRACLE NETWORK HOSPITALS. SINCE 2002, HE HAS GIVEN BACK TO COOK CHILDREN'S AND OUR PATIENTS IN A VARIETY OF WAYS.

In 2002, Hawkeye was visiting with a friend who told him about his experience as a camp counselor at Camp Sanguinity, a Cook Children's summer camp for hematology and oncology patients and their siblings. Hawkeye soon decided to volunteer as a counselor, as well.

From 2002-2006, he spent a week each year as the counselor in the oldest boys' cabin and served on the Friends of Camp Sanguinity Board from 2004-2006. He did a tremendous job of making his teen campers feel comfortable and helped them get into the groove of camp. His laid-back style added laughter to many situations and he helped make the camp experience a fun one for his campers.

After spending several years away, Hawkeye returned to Camp Sanguinity in 2014. That year, he decided to expand his support for Cook Children's beyond the campgrounds and onto the airwaves. In October, New Country 96.3 KSCS partnered with Cook Children's and Children's Miracle Network Hospitals for an inaugural radiothon event, a fundraising initiative that raised more than \$120,000.

KSCS broadcasted live from Cook Children's, commercial-free for an entire day, asking loyal listeners for generous donations to help families and children affected by illness, disease and injury. Hawkeye's commitment to the patients at Cook Children's was a big part of the event's success, including the great amount of awareness the day brought to Cook Children's and Children's Miracle Network Hospitals.

Recently, Cook Children's and Aflac, through its Duckprints program, recognized Hawkeye for his efforts in the fight against childhood cancer. Duckprints is a national program that recognizes unsung heroes in their communities who have made a difference in the lives of children and families facing cancer – and that most certainly can be said of Hawkeye.

The footprint that Hawkeye is leaving on Cook Children's is deep, and touches many lives. His time and talents are among the greatest gifts that he can give, and we are grateful that he has chosen to give of them so generously to our patients and their families.







Children's Miracle Network Hospitals Helping Local Kids

# Look for the miracle balloon in your neighborhood

and know all of the funds raised help children in our community.

## UPCOMING MIRACLE BALLOON CAMPAIGNS AND EVENTS:

LOVES TRAVEL STOPS AND

**GREAT CLIPS:** 

COUNTRY STORES: AUG. 25-SEPT. 20

OCT. 1-31

MIRACLE CHALLENGE: SEPT. 1-27

ACE HARDWARE BUCKET CAMPAIGN: SEPT. 5

MIRACLE JEANS DAY: SEPT. 7

LONG JOHN SILVER'S: OCT. 1-31

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KSCS COOK CHILDREN'S RADIOTHON: OCT. 7

LIDS: NOV. 1-30

CREDIT UNIONS FOR KIDS: NOV. 1-DEC. 5

For a complete listing of our partners, visit cookchildrenspromise.org

## Partners in our Promise

#### Hyundai Hope On Wheels (HHOW)

IS A NATIONAL PROGRAM CREATED TO PROVIDE RESEARCH FUNDS FOR INSTITUTIONS DEDICATED TO ADVANCING PEDIATRIC CANCER RESEARCH.

In 1998, a group of Hyundai dealers on the East Coast organized a local initiative to support cancer research. From there, the program blossomed into a national non-profit organization committed to helping kids fight cancer. With the purchase of every new vehicle, Hyundai makes a donation to Hyundai Hope On Wheels (HHOW). Each year, millions of dollars of grant money are allocated to pediatric cancer research facilities throughout the country.

"We're proud to be one of the leading funders of pediatric cancer research in the U.S. for the past 17 years," said Executive Program Director Zafar Brooks. "We remain dedicated to this cause, because no child should ever fight pediatric cancer alone."

Over the past several years, Cook Children's has been a grateful recipient of several HHOW grants. These allowed for funding of our Adolescent and Young Adult (AYA) program, which is for young oncology patients often caught between pediatric and adult health care systems; our oncology bereavement program, which supports our patients and their families and friends during the spectrum of their disease; and our I-131 metaiodobenzylguanidine (MIBG) program, a targeted investigational therapy that delivers radiation directly to neuroblastoma cells. And most recently, Anish Ray M.D., one of Cook Children's hematologist and oncologists, was awarded a 2015 grant for his Ewing sarcoma family of tumors

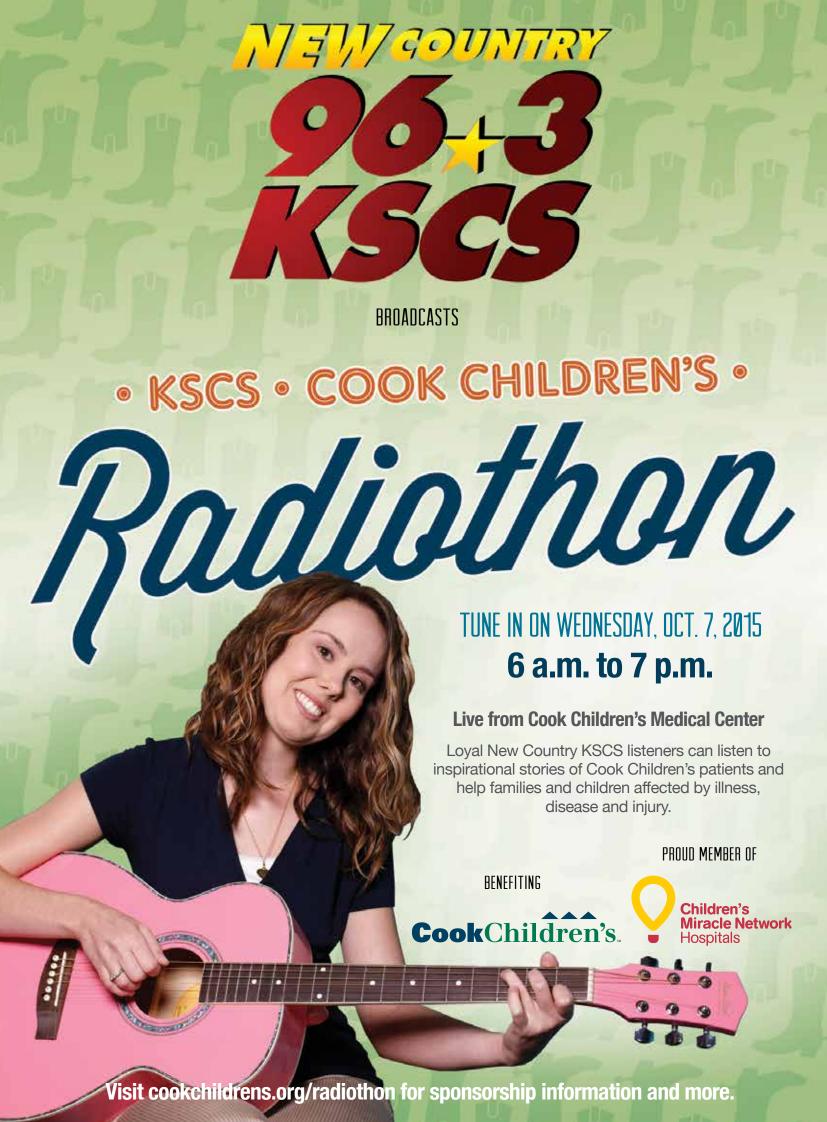
research program, which hopes to find more effective, less toxic therapies to treat the disease.

The research grants are also accompanied by a handprint ceremony, where children affected by cancer can dip their hands in paint and leave their colorful handprints on a Hyundai SUV. This vehicle travels the country to spread awareness of childhood cancer everywhere it goes. The handprints are a visual representation of the unique story of each child affected by this disease.

"We know that so much more still needs to be done to increase awareness and to improve the survival rates of children diagnosed with cancer," said Brooks. "We are committed to seeking out and funding the most innovative research programs. At Hyundai Hope On Wheels, we want the families and friends of those affected to know that we are all in this together. This is a fight we must win, together."









COOK CHILDREN'S IS BLESSED WITH MANY ACTIVE community groups WHO GENEROUSLY SUPPORT US BY HOSTING A VARIETY OF FUNDRAISING EVENTS. WE APPRECIATE ALL OF THESE enthusiastic donors AND THEIR volunteers WHO COORDINATE AND staff THESE EVENTS.

#### **CLAY SHOOT FOR CAYSON**

The Clay Shoot for Cayson was organized in 2009 in order to honor the memory of Cayson Reece Mosley and to help in the fight against child abuse. The 6th annual Clay Shoot for Cayson took place on March 6 and raised \$50,000 for child abuse prevention and awareness. Cayson's family and friends presented the check to Cook Children's Child Advocacy Resources and Evaluation (CARE) Team on April 30, a meaningful way to conclude Child Abuse Awareness Month.



Volunteers and supporters of Clay Shoot for Cayson, including Cayson's mother, Jennifer Elrod, present a check to the Cook Children's CARE Team.



2015 co-chairs Hilary Colia and Jennifer Kostohryz, 2014 co-chairs Natalie Cooper and Megan Philipp, Cook Children's Hematology and Oncology Center Medical Director Gretchen Eames, M.D., and Cook Children's Assistant Vice President of Donor Relations Jennifer Johnson.

#### **COOKIES & CASTLES**

This marked the 15th year for the Fort Worth Delta Delta Alumnae Chapter's annual Cookies & Castles event. This year's initiative grew to include six different events in Fort Worth, including two new events: the "Making Spirits Bright" cocktail party and a tween decorating party. Proceeds from Cookies & Castles benefit the Cook Children's Hematology and Oncology Center. Since its inception in 2001, Cookies & Castles has donated close to \$500,000 to Cook Children's.

#### SKIHI GOLF TOURNAMENT

The 12th annual SkiHi Golf Tournament took place on September 26, 2014. The inspiration behind the event is Kelsi Skipper, the granddaughter of Richard and Jackie Skipper, who was born prematurely and diagnosed with retinopathy of prematurity, which causes detached retinas and sometimes blindness. Thanks to Cook Children's, Kelsi has grown up to be a bright and energetic young lady. Over the years, funds raised through this event have benefited different programs across the medical center.



Lesa Breshears, Cook Children's Medical Center President Nancy Cychol, Richard Skipper, Neil McKittrick and Cook Children's Vice President of Facility/Ancillary Services Stan Davis.



#### WINE FOR A CAUSE

Wine for a Cause is a non-profit 501(c)(3) organization dedicated to funding pediatric cancer research and research protocols at Cook Children's. Wine for a Cause has been supporting Cook Children's Hematology and Oncology Center since 2010 and has raised a total of \$143,000 for neuroblastoma research.

Steve and Kristi Shilts, Walter and Ronda Stucker, Cook Children's Neuroblastoma and Stem Cell Transplant Program Director, Meghan Granger, M.D., Christine and Jeff Klote, Lizzie and Matthew Head.



#### WE WOULD LIKE TO RECOGNIZE AND THANK THE FOLLOWING COMMUNITY PARTNERS FOR THEIR RECENT GIFTS:

**CONNOR'S CAR SHOW** DREAMING THE CURE CAR SHOW **DIAMONDS IN THE RUFF** HEARTS FOR ART

**INFINITE RACE** MATT MCKEE GOLF TOURNAMENT **TCU NEXT GENERATION TCU TENNIS MATCH** 

## Generosity heals

THE PRESENCE OF A DOG CAN HAVE A POSITIVE INFLUENCE ON WELLNESS. THAT'S ONE OF THE MANY REASONS COOK CHILDREN'S STARTED THE DONOR-FUNDED

Sit...Stay... PLAY PROGRAM.

We started this program in 2014 with our first two service dogs. Cook Children's Medical Center became one of just a few hospitals in the country to have its own in-house therapy dog program. Littermates Ralph Lauren and Coco Chanel came to Cook Children's from Canine Assistants in Milton, Georgia, where they received their specialized training.

Ralph and Chanel have been hard at work at Cook Children's over the past year and a half. Ralph, handled by certified Child Life Specialist Kizzy Marco, sees patients in the Child Life Zone, as well as on the inpatient floors. Chanel sees patients in Neurology with certified Child Life Specialist Kat Davitt. Chanel helps alleviate pain in children with her work in the Pain Management clinic and while making rounds with that team.

We asked Kat and Kizzy to each share a patient experience with us.

#### Chanel and Kat

Chanel was called to the Special Procedures Area because a teenage patient believed she might die during her procedure. She was scared someone would "mess up." Chanel jumped up on the bed and snuggled up to her. Both the patient and her mom were visibly calmed by Chanel's presence. After her pre-medication, the teen fell asleep petting Chanel. Each time someone came in or out of the room, she would open her eyes to check to see if the dog was still with her. Chanel stayed until they began to roll

This was just the beginning of the bond they would share. Chanel visited frequently during her two-week visit. They created a beautiful bond and would "hold hands/paws" and snuggle in her bed. We were told that these visits were the highlight of her stay. One morning, Kat and Chanel arrived before she was awake. When the nurse told her she had a visitor and she found out it was Chanel, she was happy to get up to spend time with her. That's saying a lot for a teenager!

#### Ralph and Kizzy

After a particularly long day and week, Ralph and I made our way to the parking garage to head home. We were walking outside of the Pediatric Intensive Care Unit, where several visitors were sitting on benches. Because he had worked so hard, I decided to let Ralph choose whether to stop and visit the many folks calling out to him. He kept walking, his paws audibly dragging on the floor, until out of nowhere he made a beeline to a man sitting alone with his head in his hands. Ralph announced his presence with a gentle nudge. Surprised, the man first chuckled and then began to cry, as he pulled Ralph nearer. I'm not sure we'll ever know what was happening for that man, but I stepped back and watched as they comforted each other. At one point, Ralph even looked back at me over his shoulder as if to say, "I got this, Mom." After a few minutes, the man told Ralph he could go, but Ralph only leaned in closer. When their visit was finally over, the man thanked me

Ralph and Chanel bring healing to our patients, their families and our staff on a daily basis. In their first year at Cook Children's, Ralph and Chanel together had more than 6,000 patient visits. Seeing the direct benefits they have had on our patients, Cook Children's welcomed two more dogs, Journey and Kitty, to the family in May 2015, also thanks to the generous support of our donors.

Journey and Kitty are also golden retrievers from Canine Assistants. Journey, handled by certified Child Life Specialist Julia Smeltzer, visits patients in our critical care units. Kitty, with Jamye Coffman, M.D., helps patients who see our Child Advocacy Resources and Evaluation (CARE) Team. Led by pediatricians who are board certified in evaluating and assessing child abuse cases, the Cook Children's CARE Team provides medical evaluations, psychosocial assessments and preventive education.

Thanks to the donors who see the value that Sit... Stay...PLAY brings to Cook Children's, we were able to double the size of the program in less than two years. The amount of healing and happiness that these four dogs will have on our patients – and everyone who comes into contact with them – is immeasurable.





## Young philanthropists

Chloe Brown was diagnosed with acute lymphoblastic leukemia (all) at just 15 months old. SHE ENDURED CHEMOTHERAPY AND RADIATION TREATMENTS AND THEN, IN AUGUST 2010, NINE MONTHS AFTER COMPLETING HER TREATMENT PLAN, CHLOE RELAPSED.

Cancer is something no one ever anticipates, especially not with a young child. The diagnosis catches you off guard and rattles the entire family. Even as Rhonda and Eddie Brown prepared to help their youngest daughter battle cancer for a second time, they knew they still had to take care of their other responsibilities at home. The Browns' oldest daughter, Bailey, was entering the eighth grade, and Rhonda had to take a break from teaching to care for Chloe.

Thankfully, the family was able to lean on teachers, their church community and friends to help them juggle their split worlds at home and at the hospital. Though they were stretched thin at times, they were able to count on their tightknit Justin, Texas, community to help them make ends meet.

As a member of National Junior Honor Society that year, Bailey was challenged to come up with a service project that raised money for a cause. "I saw that there were so many other fundraisers geared toward adult cancer, but childhood cancer didn't get much attention," said Bailey.

She and her classmates decided to sell "Orange Out" T-shirts and silicon bracelets that read "I Wear Orange for Chloe." Leukemia awareness is represented by the color orange. Additionally, Bailey and her friends started wearing orange T-shirts on Fridays as a way to recognize the cause. Within two months, there were more than 600 people wearing their "Orange Out" T-shirts to support Chloe's journey and they had raised \$1,450 to donate to leukemia research organizations.

Thankfully, in September 2011, Chloe had completed her second round of treatment and was declared cancer-free. Even though Chloe was in the clear, the Browns felt the need to help families who were going through what they had just endured.

With money from Bailey's bracelet sales and pro-bono help from a certified public accountant friend, the Orange Out Foundation was born. The Browns' foundation hopes to help families financially, spiritually and emotionally as they take on childhood cancer.

A large part of Orange Out's crusade is their outreach

program. Families can count on Rhonda to deliver snack bags, drinks and toys to the hematology and oncology floor at Cook Children's Medical Center every Wednesday. Rhonda recalled a time when Chloe was inpatient and she didn't have the resources to eat one day, and that experience stuck with her. "I know all too well that the snacks I bring could be some parent's meal for the day," said Rhonda.

The foundation passes out gift cards to families in need and sponsors goodie bags for Camp Chemo, an inpatient camp put on by Cook Children's for the kids who aren't well enough to get away to summer camp. Orange Out has shuttled patient family members to and from the airport and fulfilled special requests, like bringing them specific food items or toiletries to make patients and families feel "more at home" during their hospital stay.

Orange Out hosts several fundraisers throughout the year, including the Shave Out, which occurs on the last day of August every year, the day before Childhood Cancer Awareness month begins. Hairstylists donate their time and services to shave heads, raising money and awareness for childhood cancer.

On a grander scale, the Orange Out Foundation provides an outlet for families who are overwhelmed with the chaos that life with childhood cancer brings. Their hospital visits provide face time with the families who are inpatient, giving them a resource for fellowship and understanding in a time of uncertainty and stress. Bailey and Chloe are an integral part of the foundation's work, pitching in on weekends and over holiday breaks.

Michelle, the mother of a Cook Children's cancer patient recalled, "Time and again, when we needed to vent or talk to someone who understood the hardships we were facing, they were there to offer whatever was needed."

Bailey Brown and the Orange Out Foundation are providing a much-needed service to families fighting childhood cancer.

# Noteworthy

WITH MORE THAN 50 EMPLOYEES, COOK CHILDREN'S IS PROUD TO BE AMONG THE LARGEST CHILD LIFE DEPARTMENTS IN THE COUNTRY. SO HOW DOES THAT TEAM HELP OUR FAMILIES?

\*\*Kizzy Marco\*\* Shares Her Story.\*\*

Families aren't charged for

Child Life services; however,

Cook Children's and our

donors believe that Child Life

is an essential part of the

healing process. Thank you

to all our donors who choose

to support these important

programs.

When I first moved to Fort Worth from Chicago, it felt like I was asked at least once a day, "What brought you here?" My quick response that I moved to work at Cook Children's surprised many, perhaps because it seems that if you work in health care, you can work anywhere. There is truth to that to a certain extent, but as a Child Life specialist, something told me Cook Children's was where I needed to be.

When I came to
Cook Children's, my position
required me to work anywhere
and everywhere in patient
care. One morning, I was in
outpatient surgery when, to my
surprise, an anesthesiologist
asked me to help with taking a
patient to the operating room
because the patient was very
anxious. What was even more
surprising was when a second
anesthesiologist made the same
request just a few minutes later.
I was in the middle of trying

to make a decision about whose patient to help when the second doctor let me know he would wait for me to bring his patient back. Anyone in Child Life can tell you how huge that is; the recognition that the services provided by Child Life are so vital that they are worth waiting for, even in the fast-paced world of surgery.

To an outsider, our work may appear to be fun and whimsical. I often hear comments such as "You have the best job ever; all you do is play all day" or "I wish I got paid to blow bubbles and play on an iPad." But it's important to clarify that in all things a Child Life specialist does, there is therapeutic value. I remember when I was a student in Child Life and my preceptor (trainer) was referred to as a "glorified babysitter." Though it may have stung her to hear that, it sparked an important conversation about what Child Life specialists aren't, and more importantly, what they are.

Child Life specialists are educated in child and human development; they have at least a bachelor's degree, and in many cases, a master's. They complete a semester of practicum, a 480-hour highly selective clinical internship, and must demonstrate theoretical and practical knowledge to pass a certification exam. Once certified, they are required to maintain certification by participating in professional

development and continuing education. The knowledge gained on the way to becoming a certified Child Life specialist is used to build therapeutic relationships that help patients and their families master the health care experience.

Child Life specialists help kids and their families get a better understanding of their diagnosis and treatment in a way that's unique to that family. The patient's specialist may use medical dolls, messy

activities and other forms of play to help the patient and any siblings clearly understand what they are going through. It's the work of Child Life specialists to assess the patient's development, needs and psychosocial goals. They then help to equip the whole family with knowledge and coping skills; they normalize a very abnormal environment, and perhaps most importantly, they make sure that kids have every possible opportunity to still be kids while they are here.

And yes, Child Life specialists do have the best jobs ever.

#### Written by:

Kizzy Marco, Child Life Zone program coordinator at Cook Children's and the primary handler of Ralph Lauren, a therapy dog at Cook Children's.



## What's new at Cook Children's?

THE LATEST NEWS AND UPDATES FROM AROUND COOK CHILDREN'S HEALTH CARE SYSTEM.

## COOK CHILDREN'S IN MOTION

AS PART OF JANE AND JOHN JUSTIN'S NEUROSCIENCES
CENTER AND THE COOK CHILDREN'S COMPREHENSIVE
MOVEMENT DISORDER PROGRAM, OUR NEW MOTION
LAB HELPS US BETTER SERVE PATIENTS WITH COMPLEX
CONDITIONS THAT CREATE CHALLENGES IN BODY
MOVEMENT DUE TO CONGENITAL DISORDERS OR
ACQUIRED CONDITIONS FROM ILLNESS OR INJURY.



USING ADVANCED COMPUTER TECHNOLOGY, SPECIALIZED CAMERAS, FORCE PLATES AND OXYGEN CONSUMPTION MEASUREMENTS, COOK CHILDREN'S MOTION LAB CORRELATES MUSCLE ACTIVITY, MOVEMENTS ACROSS JOINTS AND ENERGY USE. DATA FROM THE MOTION ANALYSIS, IMAGING SCANS, AS WELL AS THE PATIENT'S MEDICAL HISTORY AND PHYSICAL EVALUATIONS, HELPS OUR EXPERT TEAM OF PHYSICIANS, THERAPISTS AND STAFF MEMBERS DIAGNOSE THE TYPE OF MOVEMENT DISORDER AND DESIGN A TREATMENT PLAN THAT MEETS EACH CHILD'S UNIQUE NEEDS.

## IN THE NATIONAL SPOTLIGHT AGAIN

COOK CHILDREN'S IS EXCITED TO ANNOUNCE THAT WE RANKED IN SIX OUT OF TEN SPECIALTIES IN *U.S.NEWS & WORLD REPORT'S* LIST OF BEST CHILDREN'S HOSPITALS FOR 2015-2016. OUR RANKED SPECIALTIES INCLUDE: CANCER #40; DIABETES & ENDOCRINOLOGY #29; GASTROENTEROLOGY & GI SURGERY #45; NEONATOLOGY #24; NEUROLOGY & NEUROSURGERY #32 AND ORTHOPEDICS #32.



# GROWING BY LEAPS AND BOUNDS ... AND LEGOS

BECAUSE THE MEDICAL CENTER CAMPUS IS CURRENTLY UNDER CONSTRUCTION, WE THOUGHT THAT IT WOULD ONLY BE RIGHT IF OUR COOK CHILDREN'S MEDICAL CENTER LEGO MODEL ALSO GO UNDER CONSTRUCTION. IT TOOK ONE MASTER BUILDER AND ONE ASSISTANT 60 HOURS TO ADD JUST OVER 14,000 LEGOS TO THE MODEL. THANKS TO THE GENEROSITY OF SKIHI ENTERPRISES, OUR LEGO REPLICA NOW INCLUDES THE SOUTH TOWER EXPANSION, COMPLETE WITH CRANES.



## THE HEALING AND RELAXING POWER OF TOUCH

IN MARCH, COOK CHILDREN'S INTRODUCED OUR NEW, DONOR-FUNDED MASSAGE THERAPY PROGRAM.
THE MASSAGE SESSIONS RANGE FROM 10 TO 30 MINUTES, DEPENDING ON THE CHILD AND THEIR NEEDS. THE
MASSAGE THERAPIST SEES PATIENTS BASED ON DOCTOR REFERRALS AND TRAVELS ACROSS THE MEDICAL
CENTER TO SEE KIDS IN MANY DEPARTMENTS, INCLUDING THE HEMATOLOGY AND ONCOLOGY CENTER,
BONE MARROW TRANSPLANT UNIT, RESPIRATORY CARE UNIT/TRANSITIONAL CARE UNIT, PEDIATRIC
INTENSIVE CARE UNIT, CARDIOVASCULAR INTENSIVE CARE UNIT AND VARIOUS OTHER FLOORS. THANKS TO
THE GENEROSITY OF A DONOR, COOK CHILDREN'S IS ABLE TO BRING A THERAPY THAT'S UNIQUE IN PEDIATRIC
HEALTH CARE TO OUR PATIENTS.

## A BROADER APPROACH TO SPECIALTY CARE

COOK CHILDREN'S PROMISE IS REACHING ACROSS THE GLOBE. OUR INTERNATIONAL PROGRAM HAS A DEDICATED, BILINGUAL TEAM OF PROVIDERS TO HELP WITH ALL THE DETAILS WHEN FAMILIES TRAVEL HERE FROM OTHER COUNTRIES SO THEY CAN FOCUS ON THE HEALTH



OF THEIR CHILD. OUR INTERNATIONAL SPECIALTIES INCLUDE NEUROSCIENCES, CARDIOLOGY, CRANIOFACIAL AND CLEFT SURGERY, ENDOCRINOLOGY AND HEMATOLOGY AND ONCOLOGY. WE ARE EXPANDING OUR PROGRAMS, SERVICES AND AMENITIES TO MEET THE GROWING NEEDS OF FAMILIES NATIONWIDE AND ABROAD.

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# Cook Children's Prômise

KNOWING THAT EVERY CHILD'S LIFE IS SACRED, IT IS THE PROMISE OF COOK CHILDREN'S TO IMPROVE THE HEALTH OF EVERY CHILD IN OUR REGION THROUGH THE PREVENTION AND TREATMENT OF ILLNESS, DISEASE AND INJURY.

# Honor Roll = GIVING

THE GENEROSITY AND COMPASSION OF THESE DONATIONS HAVE HELPED ENHANCE THE LIVES OF CHILDREN WHO RELY UPON COOK CHILDREN'S FOR CARE.

**April 1 - June 30, 2015** 



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ARE GIFTS GIVEN TO EXPRESS JOY OR GRATITUDE.



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ARE GIFTS GIVEN IN LOVING MEMORY.



FOREVER YOUNG BIRTHDAY CLUBS

ARE FOR KIDS AND TEENS WHO ASK PARTY GUESTS TO DONATE TO COOK CHILDREN'S INSTEAD OF GIVING THEM BIRTHDAY PRESENTS.



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