

HEROES

THE MAGAZINE OF CHILDREN'S HOSPITAL NEW ORLEANS | WINTER 2020

Caring
for them,
with
kindness





Jazz Fest art installation provides a warm welcome for patients and families.



Contents

FOREWORD 2

John R. Nickens IV
President & CEO

NEWS 3

Extraordinary Together
Board of Trustees updates
New Chief Experience Officer
Historic cottage restoration
Topping out ceremony
Ronald McDonald House partnership

FEATURES 8

The patient experience
Innovating pediatric neurosciences

INSIDE CHILDREN'S 14

Patient Family Advisory Council
Our Palliative Care program

PHILANTHROPY 16

Three grants
New Child Life center
Smoothie King climbing wall
Spirit of Children

STATS 20

2019 by the numbers

Foreword

HEROES

Winter 2020, Volume 2, No. 1

Editor

Kristen Robinson

Associate Editor

Lynnsey Belsome

Photographers

Mike Palumbo

Frank Aymami

Seth Binstead

Sigl Creative

Contributing Writers

Lynnsey Belsome

Leslie Cardè

Debbie Grant

Mary Mouton

Kristen Robinson

Mike Strecker

Dean Shapiro

Editorial Board

Lynnsey Belsome

Special Events Manager

Jonathan Brouk

Vice President, Strategy

Robert Gassiot

Creative Director, LCMC Health

Cathleen Randon

Development Officer

Kristen Robinson

Director, Marketing and Communications

Matthew Schaefer

Senior Vice President and
Chief Operating Officer

Marykay Thevis

Communications Specialist

Jamie Wiggins

Senior Vice President and
Chief Nursing Officer

President & Chief Executive Officer

John R. Nickens IV

Chief Medical Officer

George Bisset, MD



Children's Hospital
New Orleans
LCMC Health

200 Henry Clay Ave.
New Orleans, LA 70118
chnola.org
504.899.9511

JOHN R. NICKENS IV, PRESIDENT & CEO



Friends and supporters,

It is a privilege to share the second edition of Children's Hospital New Orleans' HEROES magazine with you. 2019 was a year of investment and many exciting achievements for Children's Hospital as we transform pediatric healthcare for Louisiana and the Gulf South.

Now more than halfway through our campus transformation effort, the façade of our future campus is taking shape, but even more exciting are the people and programs that we are investing in to deliver a healthier, happier future for our children and community.

Last May, we launched new brands across the LCMC Health family – celebrating the “little extras” that make our health system and people so extraordinary. In September, we built upon the excitement of our new brand with the formal launch of Extraordinary Together: The Campaign for Louisiana's Children. Our capital fundraising campaign invites the community to join our mission to build a better tomorrow for all kids and only kids. With the goal to raise \$40 million by 2025, the funds raised through The Campaign for Louisiana's Children will enable Children's Hospital to bring innovation to pediatric healthcare for the state of Louisiana. You'll read more about the campaign in the pages that follow.

This issue of HEROES will tell stories about the patient and family experience, and how we're amplifying care delivery with the patient and family at the center. As a hospital dedicated to caring only for kids, we offer leading pediatric medicine in



an environment that allows patients to heal and thrive while still being kids! With the support of generous donors and community partners who share our vision, we're not just treating illnesses, we're delivering best-in-class healthcare for kids while taking care of the entire family.

Last fall, we announced a new partnership with Ronald McDonald House Charities that will relocate and expand their program to the Children's Hospital campus, expanding housing and resources for families in need. Our patients are also now driving to procedures in luxury motorized cars for kids thanks to the generosity of our friends at JR Motors. These are two great examples of Extraordinary Together, and how we can deliver more for our patients and families thanks to the generosity of our community. There is nothing more important than investing in our future, and our children are our future. Thank you for being part of extraordinary!

With gratitude,

John R. Nickens IV
President and Chief Executive Officer
Children's Hospital New Orleans

Extraordinary Together: The Campaign for Louisiana's Children

From the moment a child arrives to the hospital's campus, at the garage or the skybridge, inside exam rooms, surgical suites, and hospital rooms, they are beneficiaries of an exceptional team effort by a vast network of volunteers, families, donors, and friends. It is truly "Extraordinary Together," and a fitting title for the hospital's recently announced \$40 million Campaign for Louisiana's Children.

"The Campaign for Louisiana's Children is not only about the physical transformation and investment being made on our campus," John Nickens explained at the September 26 campaign launch celebration. "It's about our ability to impact the total wellbeing of kids and families. Our vision is to change the face of healthcare for all children."

Children's Hospital is well on its way to doing that, with the campus transformation now more than 50 percent complete, including the opening of the Betty and Hank Lauricella Pavilion and the soon-to-open Behavioral Health Center, the only psychiatric program in the Gulf Coast region exclusively dedicated to the mental health needs of children and adolescents in crisis, made possible with support from the Goldring and Woldenberg Foundations. A new, four-story medical tower for multi-specialty programs and outpatient services will open in phases beginning in early 2020.

The campaign is paving the way for innovations in care that include all private patient rooms, a new 28-bed Cardiac Intensive Care Unit, 45-bed Emergency Center, New Surgery Center, and Comprehensive Cancer Center. It will allow the hospital to focus more deeply on the patient and family



experience with a Wellness Campus, Palliative Care, and expanded Child Life programs, to name just a few of the campaign's priorities.

So far, over \$19 million has been raised toward the campaign's goal. "We hope you will join us in advocating for and investing in the most important piece of our future – our children," Nickens said.

By the end of 2021, the uptown campus will have added 230,000 square feet of new clinical care space and expanded innovative programs to provide unmatched pediatric expertise for all children and only children. This is Extraordinary Together.

Louellen Berger shares why she and husband Darryl have chosen to support Extraordinary Together at the September 26 campaign launch dinner.

Children's Hospital New Orleans Board of Trustees adds two community standouts

Longtime children's advocate Kaylea Hill and local television executive Tod Smith have been appointed to the Children's Hospital Board of Trustees.

Inspired by the passion and vision of the hospital's CEO, John R. Nickens IV, both Kaylea and Tod have enthusiastically embraced their new positions on the hospital's 12-member board; Kaylea as a member of the subcommittee that oversees the hospital's community benefit programs, and Tod as a member of the finance and development subcommittees.

For Kaylea, who grew up in a medical family, association with a hospital is an extension of her upbringing. She earned her undergraduate degree in journalism from the University of Georgia and

her M.Ed. in early childhood education from the University of Alabama at Birmingham (UAB).

Before moving to New Orleans with husband, Hunter, and their three children, Kaylea spent many hours volunteering at Clinic 8 – an outpatient clinic for

kids with cancer and blood disorders – at UAB Children's Hospital. Her primary duty was helping family members pass the long hours while their loved one was being treated.

"After witnessing firsthand the added stress that traveling for a child's treatment can put on a family, the beautiful environment that Children's provides for the families of patients

speaks volumes to the commitment Children's has to providing comfort not only to the patient, but to the loved ones as well. It is humbling to be a part of such a supportive and loving facility," Kaylea said. "We are so lucky to have this wonderful hospital in the city I love."

Kaylea also serves on the boards of the Louisiana Children's Museum and Le Petit Theatre.

Joining the board at Children's was a homecoming of sorts for Tod Smith, who is the President and General Manager of WWL-TV and WUPL-TV. He and current Board Chair Tony Recasner were classmates at Loyola University New Orleans.

"When I returned to New Orleans, I reconnected with Tony and met John Nickens. I listened to John's vision and it just fell into place," said Tod. "There is a culture of caring and success at the hospital, and the hospital's leadership is committed to providing the best care to the children in the region, while focusing on being a top hospital for children in the United States."

Tod grew up in New Orleans and is a graduate of St. Augustine High School and Northwestern University's Kellogg School of Management, where he concentrated in Management Development for Television Executives, in addition to earning his degree in management at Loyola University.

Together with wife, Kenya, Tod has long had an interest in volunteering at nonprofit organizations that work with youth in the community. He also serves on the boards of Covenant House, Volunteers of America, and the United Way.



Kaylea Hill



Tod Smith



New Chief Experience Officer brings “passion and humanity”

Scott Macicek, MD
Chief Experience Officer
Children's Hospital New Orleans

Children's Hospital Senior Vice President and Chief Operating Officer Matt Schaefer had one goal as he led a search for the hospital's first-ever Chief Experience Officer.

“We wanted someone who wakes up every day and thinks about the patient and family, and how to optimize their experience,” he said.

Schaefer could barely contain his excitement as he described finding the perfect candidate for this new and crucial position in Dr. Scott Macicek. The experience Macicek, a native of Lafayette, Louisiana and a graduate of LSU School of Medicine, has gained over more than 12 years working in pediatric cardiology was a major factor in his selection, according to Schaefer.

“Here is someone who can speak at eye level to both children and their families,” Schaefer notes. “Someone who is used to sitting in front of families when there is good news or when the prognosis is difficult news to share.”

While the Chief Experience Officer is a new role, the patient and family experience has always been central to the mission of Children's Hospital.

“All of us are part of it,” Schaefer said. “But we have not had someone of Scott's experience and caliber who has a unique passion for this work, and who will be continually challenging our organization to be the best it can be for patients and families.”

Macicek, the father of six children, heads a growing team of professionals focused on optimizing the patient and family experience.

“Healthcare is going through tremendous transition, and I was drawn by the opportunity to be part of an incredible leadership team and organization that is singularly focused on improving care for children in Louisiana,” said Macicek. “As Children's Chief Experience Officer, I hope to offer our patients and families a world-class experience at every point of contact.”

Historic cottage takes a turn



PHOTO CREDIT: Sigl Creative for the Davie Shoring project

The Children's Hospital campus is rich with history, including buildings like this creole cottage, originally constructed in the 1830s. A generous gift from Nancy and Dr. Stephen Hales has ensured it will last for years to come. After shoring up the building, crews carefully rotated it to sit perpendicular to Tchoupitoulas Street and Henry Clay Avenue. This was not the first time this cottage has moved. It was relocated to the corner of the property during the construction of the Marine Hospital 85 years ago. Restoration will now begin on the building as a special part of the campus expansion.



PHOTO CREDIT: Sigl Creative for the Davie Shoring project

Topping out the new medical tower

Did you know that a magnolia tree was perched four stories above the Children's Hospital campus? A crane gingerly positioned the tree last spring, as the final beam was placed on the new medical tower, marking a major milestone in the hospital's \$300 million expansion. The tradition of "topping out" a construction project dates back to the ancient Scandinavians with the placement of a symbolic tree at a new structure's tallest point.

The Children's magnolia tree was tied with special wishes for the future from patients, then raised to the highest point of the new structure which will house 12 operating rooms, a new Cardiac Intensive Care Unit with 28 private rooms, and a pediatric radiology imaging suite with updated technology for CT scans, MRIs, ultrasounds, and

X-rays. In April, the tree was planted on the campus as a symbol of the hospital's unwavering commitment to create a healthier tomorrow.

When completed in 2021, the 230,000-square-foot medical tower will be the centerpiece of Children's \$300 million transformation. The tower will expand emergency services by adding 17 examination rooms to the current 29. More rooms means doctors can see patients sooner, reducing wait times. Significant campus improvements to date include the beautiful Betty and Hank Lauricella Pavilion which is connected to a multi-level parking garage with skybridge, an enhanced

outpatient center, a lobby and registration center, a new 8,570 sq. ft. Neurosciences Clinic, expanded ENT Clinic, and 12-suite Hogs for the Cause Family Center. Look for the new Cardiac Intensive Care Unit, Surgery Center, and all new on-campus dining to open in the medical tower this year.





Ronald McDonald House and Children's Hospital New Orleans partner to expand family housing

When children have to be hospitalized, families can wind up spending weeks or even months away from home so they can be near their children. It can be very stressful, as well as costly and inconvenient, for parents and children.

Ronald McDonald House Charities provides places for families to stay close to their children at little or no cost. And soon, the Ronald McDonald House New Orleans program will relocate to the Children's campus. Plans were unveiled in early October for the renovation and repurposing of two 1930s-era buildings on hospital property between Henry Clay Avenue and State Street. Construction is set to begin in 2020.

Ronald McDonald House has been operating in New Orleans since 1983. The current, 15-unit facility on Canal Street near City Park is a 25-minute shuttle bus ride from Children's. The new Ronald McDonald House at Children's, a \$6 million project jointly

funded by Children's Hospital and Ronald McDonald House Charities, will bring family members within walking distance of their hospitalized children.

It will provide 24 family living units with a wide range of amenities, including cooking facilities, private bathrooms, and more.

With those 24 units added to the 12 existing family suites at the Hogs for the Cause Family Center, there will be close to 40 total living units on the Children's Hospital campus when the new Ronald McDonald House opens.

"We're really excited about putting these two historic structures to use," said Benjamin Whitworth, Vice President of Hospital Operations for Children's Hospital. "Having the convenience of being able to walk from the house to the hospital is going to be an immense

benefit for the families who stay here."

Whitworth added, "One of the benefits of partnering with Ronald

McDonald House Charities is that they are nationwide.

They do these houses all over the country, partnering with children's hospitals, and they know how to run their programs. They will be bringing that expertise here with them."

Founded in 1974, Ronald McDonald Houses now total 368 programs in 64 countries, providing over 7,200 total bedrooms to families. Donations are requested from those using the facilities but there is no fixed fee, and those who can least afford it may be allowed to stay for free.

The Ronald
McDonald House
will consist of
**24 family
living units**

The Patient Experience



As the voiced melodies intertwine with the strumming guitar inside the music therapy room at Children's Hospital, it doesn't take long before it's clear that the familiar chorus has morphed into a refrain that is something quite personal.

In fact, the lyrics have been custom-tailored to the patient who's now sitting in a wheelchair after narrowly surviving a horrific car accident.

"I've been told I was conscious in the ambulance but didn't know where I was," remembers 17-year old Krissa Flores, who's very lucky to be alive.

"When I came to and regained my memory, the doctors told me they were going to have to remove my left leg and put rods and screws in my broken right ankle. Beyond that, I broke my femur, my pelvis, and my back, when my car careened off the road into a light post."

The lyrics to the song Krissa and her music therapists are singing is from "The Middle," and the words really seem to hit home. "It just takes some time, little girl you're in the middle of the ride. Everything, everything will be just fine." It all revolves around the school of thought that if you can see it, you can be it. And, it's one of many inspirational ways in which utilizing the arts in therapy is enhancing the patient experience, and ultimately helping heal those children who are affected by everything from cancer and genetic diseases to traumatic injuries.

Child Life and Creative Therapies fall under the umbrella of Patient Experience and involve making every patient and family interaction a positive experience. That philosophy extends to every team member throughout the hospital, from the doctors making rounds to the cafeteria staff serving food. It involves everyone who plays a part in enhancing the experience of patients in this hospital and their families.



“When John Nickens, our CEO, came to the hospital a couple of years ago, he brought with him a new culture,” says René Guilbeau, Director of Patient Experience, Child Life, and Creative Therapies at Children’s Hospital New Orleans. “He believes it’s everyone’s responsibility to say something when you see something. So, it’s our responsibility to ask people from the get-go if they need help, to explain how the system works before problems arise, and to try to give families an overall excellent experience. This means that employees take ownership of their own ideas and decision making. We like to say ‘proceed until apprehended’ because as long as you’re doing something in the best interest of the patient and the family, you can’t go wrong.”

That take-charge culture permeates the hospital and requires tapping into the thoughts and feelings of both patients and parents. And, how better to know just what they think than to utilize questionnaires and surveys to keep abreast of what’s going on within every floor of the hospital and respond with continuous improvements and infinite attention to detail.

Patient surveys give the kind of feedback that is the impetus for change. Based on feedback from patients and families, the hospital gains insight into the patient experience from start to finish. What is their preferred style of communication? Are they receiving information related to their child’s care when and how they want to receive it? Surveys also help gauge

things like if families feel respected and if they like the food.

This program has been so successful that the hospital has been awarded the Excellence Award for patient satisfaction scores by NRC Health, twice! Children’s Hospital New Orleans was in competition with every other pediatric hospital in the country for this coveted award, and has proven, once again, that delivering extraordinary healthcare, providing exceptional experiences, and remediating issues when the hospital doesn’t live up to its own self-imposed standards of excellence is the difference between a good hospital and a great one.

The Patient Family Advisory Council (PFAC) is another example of how Children’s is placing the needs of its

patients and families first. The PFAC is known throughout the halls of the hospital. The council is comprised of ten parents of current or former patients, who advocate on behalf of all patients in the hospital. After all, who knows the patients better than their own families? Whether it's safety priorities, fine-tuning construction plans, or picking out kid-friendly furniture, everything is geared toward being the best possible hospital for the children. Serving on the PFAC is a two-year commitment on the part of the parents and involves working on the Patient Family Handbook, which provides the answers to frequently asked questions about a child's stay in the hospital, including everything from the basics of infection control, to financial services, spiritual support, and even dietary needs. The council makes rounds through the hospital to talk to other families every other month and is even working on computer and phone apps which will make life easier for patients.

When it comes to supporting the children, those who work in the Child Life arena believe that patients should be empowered to understand their own illnesses, no matter what their age, bringing healthcare education to a level at which it's easily understood. So, if a small child is to receive an IV, a teddy bear will get one first so that the patient understands ahead of time what's going to happen, and is, therefore, less fearful. It's all about feeling in charge of one's own treatment, whether you're eight or eighteen. And that message of being in charge of your own domain even extends to the art program within the hospital.

"If you own the space you're in and have a connection to it, then you feel comfortable being a part of it," says Julie Connelly, an Arts in Healthcare specialist with the hospital. "I have a background in art, running different programs for museums and schools, so when Children's saw the value of bringing art into the healthcare environment, I was immediately on

board. When patients come into a playroom and interact with me as we make art projects, these works of art end up on the walls of the hospital, which gives a sense of pride to many of our long-term patients, or frequent flyers, as we affectionately call those who routinely visit the hospital for dialysis or cancer treatments. Sometimes you have to figure out what medium works best for a patient to get out of his headspace with his illness and into a creative space. It may take a sketch pad and pencils, it may mean molding a piece of clay, or even teaching them how to sew or knit. I was in a patient's room just last week making origami cranes."

"Children do better when treatments are explained to them. They understand on their own level. Kids adapt to new things very readily, especially when they feel like they are part of the process."

What's just as important, Connelly says, is giving a child a choice, which in and of itself is empowering.

"I'm going in as the creative art lady, the friend," says Connelly. "I'm someone you can kick out of your room at any time, or tell me you're tired of doing something. I'm the person who comes in and asks if you're interested in doing one project or another, and you get to say 'no' if you're not in the mood. Many times kids don't get to say 'no' to anything else within the treatment setting of the hospital."

Studies have shown that engaging in a creative process like music, art, or even play therapy can change your mood, your perspective on life, and ultimately improve your treatment outcome. And, at Children's Hospital New Orleans, every effort is being made to alleviate the anxiety for children that so often comes with the unknowns of any treatment regimen.

"Children do better when treatments are explained to them," says Guilbeau. "They understand everything on their own level. Kids adapt to new things very readily, especially when they feel like they are a part of the process. We have even integrated virtual reality tools into our teaching techniques. It's just one item in our bag of tricks that we employ to teach our children in the way that they individually understand."

In that vein, major efforts are being made to use technology to enable healthcare providers to engage in diagnostic procedures for children without sedation. This happens by motivating children with joyful incentives. Imagine you're a six-year-

old going to your chemo treatment. But, instead of being pushed in a wheelchair to your infusion, you drive yourself in a mini-Mercedes to your appointment. Last September, JR

Motors donated small luxury motorized vehicles for kids that can be driven around the hospital by the patients to and from their own treatments. And while the children are navigating the hallways, they're being cheered on by doctors, nurses, and other patients along the corridors who know they've just witnessed something really special. It's been an overwhelming hit with the patients, and mom and dad know that what could have been a stressful treatment has been turned into a memorable moment their child will never forget. Play is a real game-changer, and ultimately therapeutic.

"We've taken away the negative thoughts about getting a particular procedure and turned it into something associated with fun," says Guilbeau. "Kids understand that there is a reward for cooperating while undergoing an MRI or CT scan. And the reward for holding still in the imaging unit is the



absolute delight in driving that car back to their room. It sounds simple, but it's about relating to children at a level that they understand, and that's what sets a hospital like Children's apart from one that caters to adults."

The numbers speak for themselves. Through August of 2019, 228 young patients (or 18% of those undergoing imaging) were able to complete their radiology study without sedation. This represents a 52% increase in the percentage from the same period in 2018, as a direct result of patient coordination with the Child Life teams.

Taking the premise one step further, General Electric is now creating an "Adventure Series" for imaging equipment that is totally kid-friendly. On the horizon for 2020, expect to see CT scanners that look like spaceships set in rooms that are painted to replicate outer space. Or an MRI machine that looks like a castle, with the entry

bed simulating a drawbridge. The five innovative themes for the new equipment were picked by asking children at the hospital what they'd like to experience.

"The noise in an MRI, even for adults, can be uncomfortably loud," says Guilbeau. "And, for a child, it can be downright scary. But, we recently had a teaching session with a 9-year-old here at the hospital who needed an MRI. The day beforehand we explained how the magnets work to get body images, and suddenly everything was cool and the child had a positive awareness of his treatment during his entire time at the hospital."

We're focused on catering everything to the patient and his or her family, at every level imaginable. And, it begins when you walk from the parking garage into the hospital itself.

"From the moment you exit the elevator and stroll across the Skybridge

high above the street, you'll notice flowers and butterflies floor-to-ceiling," says Connelly. "These pieces of art leading into the Lauricella Pavilion were made by kids at Jazz Fest. So, rather than entering a sterile clinical space, kids walk into an open-air garden of sorts."

It's a team effort and the employees are excited about being involved in a shifting culture where above all else they are putting themselves in the shoes of those they are treating, and understanding the experience from a kid's perspective.

Patient advocacy is not a new concept, but at Children's Hospital New Orleans, delivering that "little something extra" to create a partnership between patients and those caring for them means creating an environment that provides a win-win situation for everyone... most importantly, the patients whose wellbeing depends on it.

Children's Hospital supports the growth of specialized pediatric neurological services with the opening of a new and expanded **Pediatric Neurosciences Clinic**



Children's Hospital New Orleans further solidified its place as the Gulf South's leader in pediatric neurosciences with the opening of a new Neurosciences Clinic staffed by a highly specialized team that includes eight pediatric-trained neurologists and two pediatric trained neurosurgeons. The expanded 8,570 sq. ft. Neurosciences Clinic is an integral part of the hospital's \$300 million campus transformation. Doctors and staff provide multidisciplinary care for patients with cerebral palsy,

peripheral nerve and muscle diseases, and intensive rehabilitation for patients with brain and spinal cord injuries. Children's Hospital is the only center in the state of Louisiana to provide comprehensive pediatric headache management by two board-certified headache neurologists.

"With six clinic rooms, four dedicated electroencephalogram (EEG)/sleep study rooms, and three procedure-based rooms, the new clinic further advances the skilled neurologic care

provided exclusively to children," says Dr. Ann Tilton, Pediatric Neurologist and Neurology Service Line Chief at Children's Hospital. Children's Hospital has invested in innovative pediatric neuroscience care that attracts patients from all over Louisiana and the Gulf region. Children's was the first in Louisiana to use the ROSA® robotic device to perform computer-guided, minimally-invasive procedures to treat children with severe epilepsy. In January, the Rosa® was used in a



Opposite page: The new entrance to the Neurosciences Clinic. Left: The Neurosciences team celebrates the opening of its new clinic with a ribbon cutting celebration. Below: Neurosciences Clinic reception area provides a warm welcome for families.



procedure that finally stopped a 20-year-old's daily seizures.

"Being Extraordinary Together is exemplified by our investments in infrastructure and technology, along with the unmatched expertise of our pediatric-trained neurologists and neurosurgeons. That is unique and impactful for the state of Louisiana," said John R. Nickens IV, President and Chief Executive Officer at Children's Hospital New Orleans. "Our neuroscience

specialists focus exclusively on children with experts for all matters related to the brain, now housed in a state-of-the-art clinical environment."

Inside Children's

Patient Family Advisory Council (PFAC) gives kids a voice

Feedback from patients is crucial, both to their successful healing and to the success of any healthcare organization. But what about patients who haven't yet found their voices? What about the ones who are too shy or too small to speak for themselves?

That's where the Patient Family Advisory Council (PFAC) at Children's Hospital New Orleans enters the conversation. The PFAC was founded in 2017, when hospital leadership recognized the need for a uniform, structured means to gather the invaluable insights and perspectives of patients and their families.

"Patients and parents see and experience the hospital with different eyes than we do, and we wanted to understand how they experienced it. We wanted to understand how we could make it better for them," says Jamie Wiggins, Senior Vice President and Chief Nursing Officer. "Our patients and families are stressed and scared enough. We want to do as much as possible so they can focus solely on their child's needs."

Input from the 11-member PFAC team has been instrumental at Children's, resulting in alterations to the design of rooms and other aspects of the hospital's ongoing expansion, as well as changes to the hospital-provided Family Information Tips Sheet and new Patient/Family Handbook. The PFAC successfully lobbied for healthier snacks for patients and families, and engaged in discussions regarding family needs and the use of technology to improve the patient experience.

The council is currently working to provide transitional care information for Children's patients as they transition from pediatric care to adult physicians. At a recent PFAC meeting,



The Children's Hospital Patient Family Advisory Council

members also discussed plans for an upcoming holiday party for patients, efforts to gather more feedback from Children's outpatient clinic, and making online resources available for parents.

"While we help in many areas, our primary purpose is to serve as a liaison between patients and their families and hospital administration, and to help improve patient experiences," says Paul Upshaw, chairman of the PFAC, who describes the group as a vital link between children and healthcare providers.

"We do rounding (visiting patients' rooms) to gather feedback from patients and/or their families, and provide that feedback to the administration so they can make improvements, recognize exceptional staff, and correct problems quickly," Upshaw says.

The PFAC team is composed mostly of parents and other family members of patients or former patients, but also

includes hospital staff members and a hospital board member. In focusing on the care and wellbeing of patients, the PFAC considers the patient experience in a holistic manner.

"We have played a role in everything from space design decisions down to the cafeteria menu," said Upshaw, whose daughter became a patient at Children's when she was diagnosed with T-cell leukemia.

"They saved my daughter's life, and the kindness and care made a traumatic experience bearable for our family. Serving on the PFAC is an opportunity for me to give back," he says. "In many hospitals, patients don't have a voice. We proactively work with patients and their families to give them a voice, so that the hospital can make informed decisions on how to better serve them."

Special deliveries from the Pelican Krewe

When a child and family are faced with a serious illness or injury, the Children's Hospital Pelican Krewe is there, providing advanced palliative care. Below, Dr. Alexis Morvant, the Krewe's medical director, shares her thoughts on how her team works together to make every single day the best possible.

Some might say the Pelican Krewe has a sad job as we care for children and their families grappling with serious illnesses. That's not how we see it. We have the honor to bear witness to incredible stories of strength and perseverance; and most importantly, we get to figure out what "fun" may look like for families who want to make the most of what may be their child's last days.

The Pelican Krewe is philanthropically supported and gives us the flexibility to think creatively. Sometimes we use the funds to throw parties for patients stuck in the hospital on special days, to provide clothing for those who left their homes for an unexpected admission, for zoo tickets for family members to restore normalcy, and in the gravest situations, to help defray funeral expenses.

Outside for the first time

At the time, Kayden was a 14-month-old boy who had spent his entire life in the Neonatal ICU because of his prematurity. He was nearing end of life and his mother lovingly chose to protect him from escalating intensive interventions. Due to circumstances out of our control, Kayden would be experiencing end of life in our hospital.

Our palliative care team suggested to his mom that perhaps taking Kayden outside for the first time would be a special experience. When mom heard those words, she suddenly started jumping up and down with the biggest



Patient Raine Brady and family visit Audubon Aquarium this summer for a special experience

smile I have ever seen. Challenge accepted! Through an amazing multi-team effort between the transport team, NICU, nursing, respiratory team, and the Pelican Krewe, we were able to bring this precious baby boy with his hat and Mickey Mouse sunglasses outside for the first time. He received high intensive support: tracheostomy with high ventilator settings, multiple IV drips, and high dose symptom management to ensure extreme comfort. The coordination of his care and teamwork were outstanding. Afterwards, his mom said gratefully, "CHNOLA gave us the best day of our lives."

A visit to the Aquarium

Raine Brady is a precious 4-year-old little girl who was born with a rare genetic illness, Mucopolysaccharidosis type II, which will cause her life to be short despite our best medical efforts. When thinking about what living well looks like to Raine, her mom shared they hoped to one day bring her to the aquarium and to have dinner as a family.

It took nine Children's Hospital volunteers, including doctors, respiratory therapists, social workers, and more, to coordinate with the Aquarium's staff to transport Raine, ensuring that her comfort was our highest priority. It was a four-hour experience for the family, where they enjoyed a steak dinner from Houston's Restaurant under the Aquarium's Mayan tunnel as divers fed the fish above them. It was the first time Raine's family was all together since February, due to Raine's prolonged hospitalization. It was a truly magical experience.

The Pelican Krewe is expanding thanks to enormous support from the hospital's administration and the LSU Department of Pediatrics. It reflects a genuine understanding that providing the best care possible for a child includes a strong palliative care program that supports families in unique ways during their most emotional time.

By: Alexis Morvant, MA, MD
Pediatric Palliative Care

Philanthropy

Three cheers for three grants for patients, families, and the community

Talking to children before they are able to talk back is a surefire, but sometimes overlooked, way to boost brain development and ensure future success in school and life. Encouraging and educating parents of young children about the power of such language nutrition, along with helping ventilator-dependent patients and their families live freer, fuller lives and making sure kids get their proper immunizations were the driving forces behind three major grants Children's Hospital received in 2019.

1

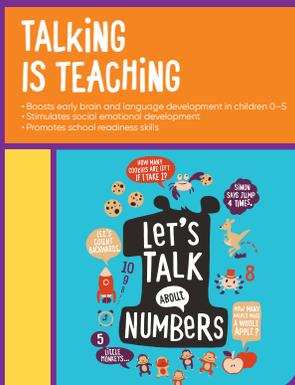
Kohl's Cares extended funding for the "Talking is Teaching: Talk, Read, Sing" campaign launched in 2018 in partnership with Children's Hospital and the Clinton Foundation's Too Small to Fail initiative. The campaign distributes toolkits and places signage around New Orleans encouraging parents and caregivers to engage children, beginning at birth, in everyday language interactions such as describing objects seen during a walk or bus ride, singing songs or reading stories.

2

Thanks to a generous grant from the **Charles and Elizabeth Wetmore Foundation**, the team of nurses, social workers, respiratory therapists, and educators with Children's Ventilator Assisted Care Program can continue to provide ventilator-dependent children and their families with ongoing training and support in equipment care, nutrition, transportation needs, scheduling appointments, and numerous other challenges and opportunities for children who require mechanical respiratory support at home.

3

Methodist Health System Foundation extended their support of the Greater New Orleans Immunization Network for three more years. The funding will expand Children's School Kids Immunization Program (SKIP). The goal of SKIP is to increase immunization coverage for school-age children by performing immunization record assessments and offering training and tools for school personnel, as well as immunization education for teachers, parents, and students. The program includes immunization drives and free vaccines.





Philanthropy helps kids play their way to better health

Supporting patients and their families on the journey from diagnosis to health is not child's play.

Or is it? Research has shown that fostering an environment that encourages play and creativity, as well as building opportunities for families to relax and rejuvenate is vital to successful pediatric care.

That's why a signature pillar of Extraordinary Together, Children's Hospital's capital campaign, is devoted to enhancing the patient and family experience, and supporting ways for the arts and play to advance healing.

This is a primary goal of the soon-to-open Child Life Center at Children's. It is also close to the heart of Whit and Maureen Huguley, who recently made a \$150,000 commitment toward the new center.

Slated to open in the spring of 2021, the Child Life Center will feature age-appropriate playrooms and activity spaces for patients and their siblings, while also providing family support services. The Huguleys, long-time supporters of Children's, have firsthand knowledge of the importance

of such offerings from their own experience as the parents of several Children's patients.

Maureen and Whit, who recently became an emeritus member of the Children's Board of Trustees after nearly 18 years of service, will recognize their own caregivers by naming the multi-purpose area of the Child Life Center, which their gift will help fund, in honor of their mothers Agnes McLindon and Katherine Huguley.

Louellen and Darryl Berger also know Children's Hospital well. Through minor injuries and serious illness, Children's has cared for the four Berger children. When discussing their involvement with the capital campaign, the Bergers expressed a passion for supporting something that would give patients, their siblings, and their parents a place to find respite from routine appointments, tests, and treatments.

Sometimes the most extraordinary gifts support the most ordinary opportunities that families outside of the hospital might take for granted. And so the Bergers decided to make a gift of \$150,000 for a playground on the



future wellness campus, which will also feature lush landscaping, walking paths, family housing, and other amenities. But they are not alone. To further the hospital's commitment to family wellbeing, The Eugenie and Joseph Jones Family Foundation has also made a \$20,000 commitment for playground construction. Philanthropic support is vital to building environments of health that create an extraordinary experience for both patients and families.

Rehabilitation rocks with Smoothie King climbing wall



Climbing a mountain is an often-used metaphor to describe a patient's medical journey. But that metaphor becomes literal for many young patients at Children's Hospital New Orleans, where the treatment plan includes scaling the Smoothie King Rock Climbing Wall, a popular rehabilitation tool located in the Sensory Treatment Room at Children's Outpatient Rehabilitation Clinic in Metairie.

“The rock climbing wall is such a versatile tool. For some, it is a physical test to climb to certain parts on the wall. For others, it might be a cognitive test for them to plan how they will climb it.”

“The kids love the wall!” says Todd Danos, Director of Rehabilitation Services at Children's. “We have not had one child who has not enjoyed spending time using it. It certainly brings a ‘fun factor’ to treatment.”

But more than a good time, the 8'x12' wall, installed last spring through a generous donation from Smoothie King, offers benefits for every conceivable condition.

“We are able to use the wall on any patient who comes in for physical, cognitive, or sensory treatment,” Danos says. “The rock climbing wall is such a versatile tool. For some, it is a physical test to climb to certain parts on the wall. For others, it might be a cognitive test for them to plan how they will climb it.”

And the wall is a hit for kids of any age, according to Danos. “Sometimes the parents are more excited than the kids. It is great for a parent to see their child do something on the wall that they might not do in another setting.”

Danos says ensuring the safety of the children using the wall is job number one, so trained therapists continually supervise, guide, and support climbing kids.

As with any mountain waiting to be conquered, climbing the rock wall is both a physical and psychological achievement for the kids, Danos says. “When the child feels like they have accomplished something, they feel better about themselves, which ultimately increases their participation in the rehabilitative process.”



Spirit Halloween stores raise funds for Child Life

Since 2010, Spirit Halloween stores have partnered with the Child Life and Creative Therapies team at Children's Hospital New Orleans to raise funds and awareness for the hospital program. The annual fall fundraising campaign, "Spirit of Children," raises money from the sale of Halloween costumes and other items in pop-up stores throughout the Greater New Orleans area.

"We have the most wonderful supporters for this campaign," said René Guilbeau, Children's Director of Patient Experience, Child Life and Creative Therapies. "We sincerely appreciate all the hard work, time, and effort it takes the Spirit Halloween team to make this campaign not just happen but grow year over year."

The shops, which are open August through October, sell Halloween costumes, decorations, and other themed items. The fundraiser has grown significantly over the years and in 2019 the campaign raised over \$136,000 for the hospital. "That amount just shows how committed the Spirit Halloween team is to our mission," Guilbeau said.

The effort here in New Orleans is part of a larger campaign by Spirit Halloween stores across the country to invest in local Child Life programs which aim to make hospitals less scary for kids and their families. In total, 141 hospitals across the United States and Canada benefit from the Spirit of Children fundraiser each year.

"We meet with store leadership in the summer to discuss the campaign," Guilbeau said. "They're always looking for ways to make it bigger, not only in terms of dollars, but in creative ways to share the Children's Hospital story. I've never seen a group of more dedicated people."

In addition to the pop-up stores in the community, the Spirit Halloween team brings Halloween fun to the patients at Children's by setting up a store at the hospital. Patients and their families get to choose their costumes at no cost and attend a special Halloween party, just for them.



2019 AT A GLANCE

Children's Hospital New Orleans



106,371
SPECIALTY
CARE VISITS



Pediatric Primary
Care
Visits **141,498**

SURGICAL
CASES

8,950

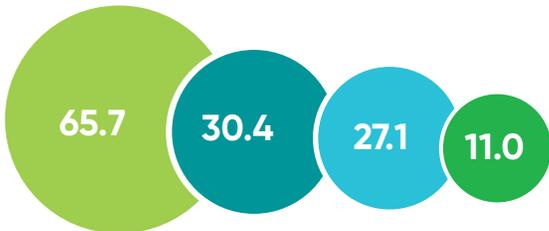


344
Helicopter
Transports

TOTAL
TRANSPORTS

612

AVERAGE DAILY CENSUS



Acute
Care

Behavioral
Health

Neonatal
Intensive
Care

Pediatric
Intensive
Care

139



AVERAGE INPATIENTS
PER DAY



52,254

TOTAL EMERGENCY DEPT. VISITS



FULL TIME
EMPLOYEES

1,851



940

VIRTUAL VISITS

Serving patients from all
64 parishes
in Louisiana



Pediatrics clinics

Do a little something extra for the kids at Children's Hospital!

Host a Community Fundraiser



Small acts of kindness become **extraordinary** when we do them together. Since 2017, nearly **\$500,000** has been raised – **\$1** at a time – by individuals and organizations willing to host their own fundraiser!

Join our community of fundraisers.
Make it uniquely your own:

- Lemonade Stand
- School Bake Sale
- Golf Tournament
- Fishing Tournament
- Chili or Gumbo Cookoff
- Dinner Party
- Car Show
- Walk-a-thon
- Birthday Fundraiser
- Car Wash
- Facebook Fundraiser
- Raffle



However you choose to raise funds, whether it's a neighborhood yard sale or a company golf tournament, our team is here to help you make it a success.

Contact Candace Burnett, Development Officer,
at 504.894.6876 or candace.burnett@LCMHealth.org
to get your community fundraiser started today!

chnola.org



Children's Hospital
New Orleans
LCMC Health



Children's Hospital
New Orleans
LCMC Health

Campus transformation continues with the opening of the new walkway connecting the Henry Clay Ave. and State St. sides of campus.