

SECURING THE PROMISE

SPRING 2020

WE ARE
Le Bonheur
STRONG!

COVID-19: Innovation Under Pressure

- ♥ A New Normal
Family finds solace, stability at FedExFamilyHouse during pandemic
- ♥ Giving Support, Sharing Knowledge
Son's TSC diagnosis leads to innovative procedures and opportunities to give back

Le Bonheur
Children's Hospital

Le Bonheur Children's Hospital in Memphis, Tenn., treats more than 250,000 children each year through community programs, in regional clinics and a 255-bed hospital that features state-of-the-art technology and family-friendly resources. Our medical staff of more than 240 physicians provide care in 45 subspecialties.

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Support Le Bonheur

For more information about ways to support Le Bonheur Children's by volunteering, attending events, developing partnerships and giving financially, please visit lebonheur.org/ways-to-help or call 901-287-6308.

www.lebonheur.org/secure

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MESSAGE FROM THE PRESIDENT

Dear friends,

Le Bonheur remains a bright light for our community, even in these uncertain times.

Your generous gifts have helped us fight for children and those affected by the COVID-19 pandemic. You are making a difference.

In the following pages, you'll get a glimpse of some of the many ways our community at large has banded together to support our employees, doctors and the children in our care. Some have provided meals for our staff, others developed protective equipment for care of children with suspected COVID-19. All of these gifts are appreciated.

Because of you, we are here for all of the children who need us – whether for COVID-19, a heart transplant, physical therapy or a well-child visit. Keep reading to see some of the ways that your gifts have allowed us to innovate and provide care that's safest for families.

Your gifts allow us to respond quickly, and we hope you will continue to support Le Bonheur – as our needs continue to change.

Thank you for generously giving during a turbulent time. Your gifts improve the lives of so many children, whether they enter our hospital doors, stay at FedExFamilyHouse, visit one of our many clinics or engage in innovative telehealth services designed to keep them safe while providing superb care.

Your support makes all the difference.

Sincerely,



Michael Wiggins, MBA, FACHE

President

Le Bonheur Children's Hospital



Innovation Under Pressure

Across departments, Le Bonheur Associates and providers find ways to help kids during COVID-19 pandemic



Mary Kate Webb now receives her needed therapies over video, thanks to a growing telehealth program. While COVID-19 has stopped her home visits, therapists at Le Bonheur Children's have found a way to ensure Mary Kate gets the care she needs.

One week of telehealth

Doctor's visits: 1,829
Therapy: 683



Safe at home

Families use technology for vital medical, therapeutic services

22-month-old Mary Kate Webb receives most of her nutrition from a feeding tube in her stomach, but she'd been close to learning how to eat by mouth when the COVID-19 pandemic hit the Memphis area.

"I feel like we've worked on so much," said mom Meredith Webb. "She's continuing to progress, and it would be hard for me to know what to do next."

She didn't have to.

Le Bonheur therapists quickly developed telehealth sessions for Mary Kate's physical and speech therapy – and were able to cater her services so that she could still receive them at home.

Mary Kate has Wolf-Hirschhorn Syndrome and suffers developmental delays from her diagnosis. She has been working with therapists since she was just a few months old, and missing therapy appointments puts her at risk for falling behind.

"I wasn't sure how it would go at first," Meredith said of the therapy. "Initially, she was a little bit confused. Now, she gets it and I see a lot of value in it."

Donor support allowed Le Bonheur clinicians to quickly expand telehealth services within days of the first reports of COVID-19 in Tennessee, ensuring that children didn't miss important doctors visits or clinic appointments.

Today, children like Mary Kate who rely on services still have continuity of care in the safest possible environment.



Licensed Psychologist Mekel Harris, PhD, NCSPP, is able to continue mental health support to families thanks to telehealth technology.

Therapeutic gifts

Investments allow mental health support to continue

Licensed Psychologist Mekel Harris, PhD, NCSPP, knows better than many the effects that parent and caregiver mental health have on the physical health and well-being of children.

And no time has this been more apparent than during the current COVID-19 pandemic.

Harris, a Family and Employee Assistance Program (FAP/EAP) provider, has continued to provide mental health support for families – above and beyond what they already do for families facing the hardest times with their children in the hospital.

“Offering therapy services during this time has afforded some families the opportunity to remain socially connected and emotionally supported in a period of incredible uncertainty,” says Harris. “This is particularly helpful for families who now have limitations on the number of visitors they can have within the hospital environment.”

Focusing efforts on the Neonatal Intensive Care Unit (NICU), the Social Work team continues to offer mental health screening for patients and families upon admission. And thanks to technology, social workers can continue the same process of referring families to Harris for psychological assessment and support as needed.

“I am able to offer telehealth or telephone therapy services for continuity of care where there is concern about potential COVID-19 exposure,” says Harris. “Alternatively, I am able to continue meeting with families at bedside while practicing social distancing and exercising universal precautions.”



COVID-19 has halted in-person events and activities in the hospital. But Child Life Specialists ensured the annual Easter celebration continued by using an app to take photos of patients with the Easter bunny.

Get creative

Donor-funded Child Life programs bring normalcy to hospital

Parties, concerts and game shows are just a handful of activities that the Child Life team provides on a daily basis. But how do you provide activities when children and families need to stay at least 6 feet apart? Flex your creative muscles.

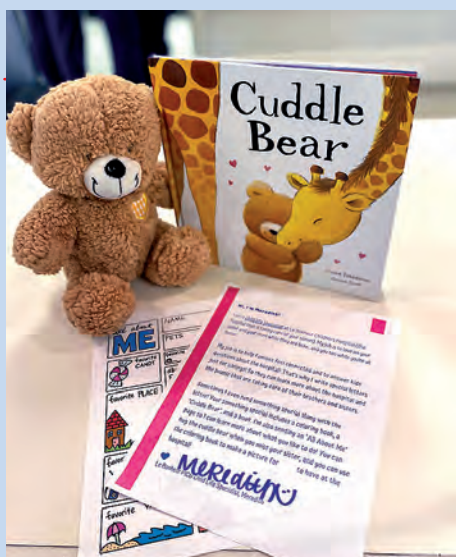
Le Bonheur's Child Life team has looked to technology to help them provide normalcy for children during COVID-19, moving in-person programming to the hospital's closed-circuit TV channel, creating a virtual Easter egg hunt and using an app for children to take pictures with the Easter bunny from their hospital rooms.

Le Bonheur's 31-member Child Life team provides evidence-based therapeutic play and education to address the psychosocial needs of children. All Child Life activities and events are exclusively funded by donors.

"These activities give patients a way to engage in play with our team and other patients and families throughout the hospital, even if they aren't able to interact face to face," said Child Life Director Jessica Liles.

Certified Child Life Specialists are also catering the care they provide based on need. Visitor limitations don't allow for brothers and sisters to visit, so the PICU Child Life Specialist created sibling bags for families to take home. They hope to make the siblings feel loved and supported from afar while they are separated from their family members.

And what is a potentially ill parent supposed to do when they can't enter the hospital to see their child? The NICU Child Life Specialist intervened with a technological solution using video call for families when a mom waiting on the results of her COVID-19 test wasn't able to enter the hospital to see her newborn.



Sibling bags are a way to keep brothers and sisters involved in their sibling's care. Pediatric Intensive Care Unit Child Life Specialist Meredith Norton, MA, CCLS, has assembled bags to introduce Child Life to siblings and continue providing sibling support from a distance.

Food as medicine

Community-based health workers meet needs for food, formula

Children living with chronic conditions like diabetes and asthma were on the minds of Le Bonheur's community health workers when they started calling home-based clients. Their concern: would children already living with food insecurity have access to the nutrition they needed to stay healthy during a pandemic?

With schools closed, Le Bonheur staff knew that families would be challenged and stretched. Nurses quickly began calling and offering video chat with families to assess their needs – more than 300 families and growing.

"These children are already at high-risk of hospitalization because of their chronic medical conditions," said Allergist and Immunologist Christie Michael, MD, who serves as medical director of a community-based program for at-risk children with asthma. "Sometimes, access to nutritious food can mean the difference between children staying safe at home and having to be hospitalized."

Community health workers have made no-contact deliveries of food and necessary supplies for these families in need.



Many of Le Bonheur's most vulnerable patients are in need of vital supplies including adequate food. Community health workers have made no-contact home deliveries to these families.



Carter Evans checks out the food and supplies left at his door by a community health worker.

Protecting our Heroes

University of Memphis converts lab to 3D print face shield frames for Le Bonheur health care workers

The University of Memphis began running its 3D printer 24 hours a day to create face shield frames for health care workers.



Dr. Ebrahim Asadi, University of Memphis Mechanical Engineering Assistant Professor, demonstrates the 3D-printed face shields.



Le Bonheur Surgeon Dr. Trey Eubanks (far right) and Chief Medical Officer Dr. Barry Gilmore (second from right) examine the new face shields.

How can you send a soldier to battle without a helmet?

In the war against the novel coronavirus, our soldiers are front-line health care workers, and their armor is medical-grade personal protective equipment, or PPE, like respirator masks, disposable gowns and face shields – which are facing a global shortage.

Thanks to the ingenuity and support of our community, solutions are being found to protect the health care heroes at Le Bonheur Children's Hospital.

At the onset of the outbreak, Le Bonheur leaders took a proactive approach and quickly calculated how much PPE was on hand and would be used on a daily basis, how long that supply would last and how much more would be needed during this crisis.

Face shields, which are worn over masks to protect workers from respiratory droplets or other bodily fluids, were identified as a critical need.

Before supplies ran short, Le Bonheur Chief Medical Officer Dr. Barry Gilmore contacted the state to find out how Le Bonheur could receive additional face shields, and quickly.

Dr. Gilmore and Le Bonheur Surgeon-in-Chief Dr. Trey Eubanks were soon in contact with University of Memphis Mechanical Engineering Assistant Professor Dr. Ebrahim Asadi, who runs a 3D printing lab.

The U of M converted its lab to create face shield frames and began running its 3D printers 24 hours a day. A face shield is made of three components – the plastic frame, an elastic band and a detachable plastic sheet covering. Dr. Asadi worked with other universities across the state to gather all necessary components, and the U of M made its first delivery of 50 new face shields, which can be easily cleaned and reused, to Le Bonheur at the end of March.

"We appreciate the support of community partners like the University of Memphis during this uncertain time," said Dr. Gilmore. "Their offer of help means so much to our clinical experts who are working around-the-clock to help keep kids healthy and well."

By mid-April, the lab had reached its goal of creating 250 new face shield frames, partnering with medical supply company MCR Safety to produce all components locally for quick delivery to area hospitals.

"This opportunity has been really incredible," said Asadi. "I feel lucky I could do something to help doctors and nurses who are on the front lines, saving lives."



Inspired to give back, community members have found ways to support Le Bonheur and its health care heroes in the past several weeks. Above, FedEx donates 2,000 N95 respirator masks, a valuable and limited resource needed to care for suspected and confirmed COVID-19 patients. When the call for more blood went out, Le Bonheur staff and community members provided enough blood to save 83 lives (right). And below right, Le Bonheur's Emergency Department receives one of the 5,000 meals that local restaurants and donors have provided.



Critical Support for New and Expecting Moms and their Babies

Le Bonheur Nurse-Family Partnership provides vital resources for those most vulnerable during COVID-19 pandemic



Community Health Nurse Beth Pletz (left) visits new mom Dominique Jones. Beth is able to continue to provide medical and social support to moms like Dominique and bring her vital food and supplies.

Pregnant, afraid and alone.

The novel coronavirus pandemic has intensified an urgent need for support for many expecting mothers in the Memphis area.

A Le Bonheur community outreach program, Nurse-Family Partnership (NFP), is stepping in and stepping up to help hundreds of new and expecting moms and their babies.

"Everything is more difficult right now," said Le Bonheur Community Outreach Maternal Child Director Sandra Madubuonwu, who is in charge of the hospital's NFP program. "Our clients are in isolation and resources are harder to secure for them. Even before the pandemic, our nurses would sometimes be the only support these moms have."

Nurse-Family Partnership changes the future for the most vulnerable babies born into poverty by giving a first-time mom trusted support through nurse home visitations from pregnancy to her child's second birthday. The program is backed by more than 40 years of scientifically-proven outcomes for mom and baby.

At the onset of the COVID-19 outbreak, Le Bonheur NFP quickly transitioned to "virtual visits" for every mother enrolled in the program.

Out of 176 enrolled family members, 14 did not have smartphones or video conferencing capability. While these moms were still able to speak regularly with their nurse partner

over the phone, the national NFP office recently purchased smart phones for these clients so that every mom enrolled in the program can have some semblance of face time with a nurse.

Le Bonheur NFP nurses are also providing contact-free deliveries of essential items like food, milk and diapers for their clients.

Some resources have begun to dwindle because supply is low.

"We are lucky to have local funders that have been so helpful," said Madubuonwu.

One example is an impact fund created through partnership with Slingshot Memphis. The Le Bonheur NFP team is using those funds to provide support for their clients' utility bills, as many have lost jobs but still have bills accruing.

"If a mother is supported in her pregnancy, the outcome of that investment will change a generation," said Madubuonwu.

Her team is currently accepting new referrals and enrollments to help as many expecting mothers as they can during this time.

"The only thing I don't like about this program is that more mothers don't have access to it," said Charol Hewitt, a program participant.

Hewitt's son, Gavin, turns 2 next month. The program, said Hewitt, changed both of their lives.

Hewitt's nurse partner, Stephanie Washburn, counseled her through prenatal appointments, helped her prepare for labor and delivery, tackled breastfeeding issues once she arrived home and supported her through post-partum depression.

"It's hands-on, frontline, factual care," said Hewitt. "This program played a major role in my son's life and mine."



Nearly 2-year-old Gavin Hewitt and his mom, Charol, are two of many who have benefitted from life-changing care through Nurse Family Partnership.

A New Normal

Family finds solace, stability at FedExFamilyHouse during COVID-19 pandemic

by Amy Gagel, mother of 6-year-old heart transplant recipient, RaeAnn

After months of living between the hospital and FedExFamilyHouse, my husband, David, and I received the long-awaited news from the wonderful pediatric cardiology team at Le Bonheur Children's Hospital — a heart was available for our 6-year-old daughter RaeAnn.

This has been a long road for us with multiple long-term stays at the hospital and countless days spent at FedExFamilyHouse. Following her heart failure diagnosis, we knew our sweet girl would have to get a heart transplant. But what we didn't know were the changes that COVID-19 would bring to our world.

After successful transplant surgery, we moved to FedExFamilyHouse while RaeAnn recovered. It was truly a blessing to have free lodging while she received the best medical care. The outstanding staff at FedExFamilyHouse made it feel like home, providing play areas, a kitchen to prepare healthy



Thanks to FedExFamilyHouse, our family had a comfortable place to stay while RaeAnn recovered from her heart transplant during COVID-19.

meals and a home base close to Le Bonheur. As RaeAnn has gotten stronger during her recovery, we looked forward to exploring Memphis: visiting museums, playing in parks, attending the symphony and enjoying family time with our two older children.

All of these plans changed and our daily rhythm — so important for a child like RaeAnn — was upended by the coronavirus outbreak. Since the arrival of the virus, our family has been isolated from the outside world. As a new heart recipient, RaeAnn is in the high-risk category for COVID-19.

Constant handwashing and wearing

a mask are not new to her, but social distancing for an extrovert like RaeAnn has been a challenge. No more visits from family and friends, including her siblings. She misses interacting with her favorite occupational and physical therapists and hugging her beloved medical staff. Any hopes of playing with other children and exploring Memphis have been put on pause as we are fiercely committed to staying isolated for her protection.

Our new normal starts at 6:45 a.m., waking up in time to administer the first of nine doses of medication throughout the day. We have breakfast and playtime and return to our suite for telehealth therapy sessions. RaeAnn misses these invaluable face-to-face sessions, but riding a therapist-provided bicycle around the grounds has been a bright spot. We spend the rest of our day together reading, playing and napping.

As we remain vigilant to protect RaeAnn, we are thankful for the joyful staff at FedExFamilyHouse. We are greeted daily by Sandra and Cayce, who are always willing to help and listen. They have taken amazing care

RaeAnn waits for her heart to arrive on the day of her transplant.



of us, even adjusting to our schedule and cleaning our room while we are downstairs. FedExFamilyHouse has become our safe haven during a scary time. The staff gives our family an important social connection during a time of isolation.

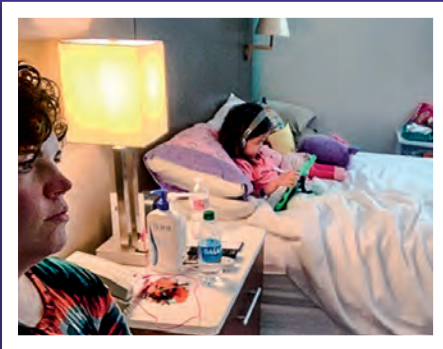
With the world struggling to cope with COVID-19, the teams at

FedExFamilyHouse and Le Bonheur Children's Hospital have provided stability and invaluable resources. The excellent care and genuine concern for RaeAnn's well-being has been a true blessing during an uncertain time.



Our daughter RaeAnn, 6 years old

A Day in the Life of RaeAnn



FedExFamilyHouse gave us a comfortable place for RaeAnn to recover from her heart transplant in the midst of the COVID-19 pandemic. Our days start at 6:45 a.m. when RaeAnn takes her first dose of medication.



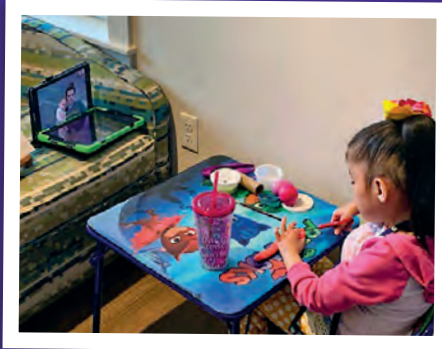
While many of RaeAnn's therapy appointments take place via telehealth, because FedExFamilyHouse is so close to the hospital, our physical therapist was able to come by to have an outdoor therapy session – from a safe social distance, of course!



We spend our days enjoying the sunshine and finally being able to play outside! RaeAnn loves riding the tricycle that her therapists provided to encourage her recovery.



Finally we can enjoy picnics in the courtyard at FedExFamilyHouse together!



The threat of COVID-19 coupled with RaeAnn's heart transplant means that we have to be incredibly careful about social interaction. We are thankful for the technology that allows us to stay connected while keeping RaeAnn safe – whether with family and friends or our medical staff and therapists.



To show our appreciation for their hard work and companionship, we cooked lunch for FedExFamilyHouse staff before we were finally able to go home. We are so grateful for each one of them!

A Lifelong Passion

Donor's dedication to helping the most vulnerable supports Le Bonheur's endowment

Natalie Charach remembers when her mother, in her last years, pulled out a piece of yellow ledger paper with a list of charities and dollar amounts.

"She didn't have a penny to her name, but she had a complete list of all the charities. Five dollars, ten dollars, fifteen dollars ... and that was her wish that when she died, we give. She was always generous. I got it from her, I know," said Natalie.

The roots of Natalie's generosity – and boldness – started many years earlier. When she was 6 years old, her father died of complications from appendix surgery. Her mother was left a widow with three young girls in Pennsylvania mining country. She assumed her husband's business of driving a two

and a half-ton truck up the mountains to sell clothes to the miners.

"They had little shacks," Natalie vividly remembers. "Some had wood on the floor, but most had dirt floors. There wasn't any furniture except a table and four chairs, maybe a beat up couch. They made maybe \$10 a week. I think my mother gave most of [the clothing] away."

Those formative years influenced Natalie's lifelong passion of helping others. She and her late husband, Manny, formed the Manat Foundation, which has supported countless humanitarian causes. She is passionate about giving back and believes anyone who has the ability to give, however small, should do so. She has a

charismatic personality, a twinkle in her eye and a ready smile.

"I want to do as much as I can until I don't have



Natalie Charach and her late husband, Manny, formed the Manat Foundation to support humanitarian causes, including Le Bonheur Children's Hospital's endowment, to care for children for years to come.

any money left. I want to see it all put to use before I die. That's my goal – to make sure the money goes where it is supposed to go. When I give money, I want it to help provide care and lift burdens for patients and families," Natalie said.

"I want to do as much as I can until I don't have any money left. I want to see it all put to use before I die. When I give money, I want it to help provide care and lift burdens for patients and families."

Natalie Charach

The Manat Foundation recently made a gift to Le Bonheur Children's Hospital, which was inspired by Natalie's personal desire to help others, especially children who are at their most vulnerable. She first heard about Le Bonheur from her dear friend, Marge Duncanson, who had been impressed with the wonderful care the hospital provided to her nephew.

Natalie related a story from when they lost their daughter to cancer in 1989. Among the families she encountered in the hospital during her daughter Janice's last days was "... a man who was struggling to care for his children and his dying wife. He didn't have enough money to travel between home and the hospital," Natalie said.

Natalie, with her generous spirit, helped him financially so he could stay close by. "I just felt so sorry for that man. It was heartbreaking," she said.

In another personal story, Natalie described how her son Jeff was born weighing just 3 lbs., 2 oz. and required additional medical care. He spent the first three weeks of life in an isolette in a neonatal intensive care unit, which helped him gain strength and ultimately thrive on his own.

The Manat Foundation's gift to Le Bonheur's endowment will help ensure exceptional care for future generations of children. Natalie's gift is recognized at the entrance to the hospital's Infant Toddler Unit where a plaque is placed in honor of her son, Jeff.

"There are so many people who need help, and I get such joy giving help. I enjoy hearing about the good work Le Bonheur is doing," Natalie said.



Lifetime income for you. Life-saving care for children like Lincoln.



A planned gift to Le Bonheur Children's Hospital can help ensure that exceptional care will always be available for children like Lincoln, who has waited 214 days (and counting) for a new heart.

At a 20-week ultrasound, his parents received the news that Lincoln's heart was on the wrong side of his chest. He had a laundry list of congenital heart defects.

After his birth they came straight to Le Bonheur where they have received world-class care, including four open-heart surgeries, in the Heart Institute — one of the top 10 heart programs in the country.

In January 2020, doctors implanted a ventricular assist device (VAD) in Lincoln's heart to keep it beating. Lincoln and his family have been waiting in the hospital for his new heart ever since.

Help ensure that all children and their families will find life-saving care and hope at Le Bonheur today, tomorrow and for years to come.

A charitable gift annuity provides lifetime income for you and long term benefits for Le Bonheur. In exchange for a contribution of at least \$10,000 in cash or appreciated stock, Le Bonheur can offer you a fixed annual payment for life based on your age at the time of the gift.

For more information contact Cathy Wilson at 901-287-5575 or catherine.wilson@lebonheur.org or visit <https://lebonheur.planmygift.org/charitable-gift-annuities>.

Le Bonheur
Children's Hospital
Where Every Child Matters

The Schifani brothers, Adam, Nick and Paul, have a mission of gaming for a good cause. They established Nerd901 to encourage Memphians to embrace whatever “nerdy” pursuits they might enjoy and have used that platform to give back to Le Bonheur.



Gaming for Good

Brothers build community of gamers to support Le Bonheur

The Schifani brothers – Adam, Nick and Paul – have a mission: gaming for a good cause.

In 2015, Adam and Nick Schifani noticed an undercurrent in Memphis culture.

“It’s a great city for sports, but we knew that there was a movement of people into pop culture, too,” says Nick. “Video games, movies, comics ... We thought,



let’s start an outlet.”

And so they launched a blog, Nerd901.

In over the last five years, they’ve expanded their team, kicked off a Nerd901 podcast and covered everything from comics and video games to wrestling. Their goal, says Adam, is to build a “positive community.”

"Whatever you're nerdy about, do it! Be proud of it, run with it," says Paul Schifani, who creates Nerd901 content alongside his brothers.

They've put that positive spirit into action for Le Bonheur, holding annual fundraisers and running gaming days for patients and their families.

"It's personal for us," says Nick.

Adam's 4-year-old son, Nolan, was diagnosed and treated at Le Bonheur for Type 1 diabetes; Nick's wife, Summer, is a Le Bonheur nurse.

In 2018, the Nerd901 team held a 24-hour Extra Life stream on Twitch, donating all proceeds to Le Bonheur. Extra Life, an online fundraising community, allows gamers to stream in support of Children's Miracle Network Hospitals.

2018 was, the Schifanis joke, a "rag-tag operation."

"We were like, 'Oh, we know how to turn a webcam on and we have some gaming consoles. Let's do it,'" laughs Nick.

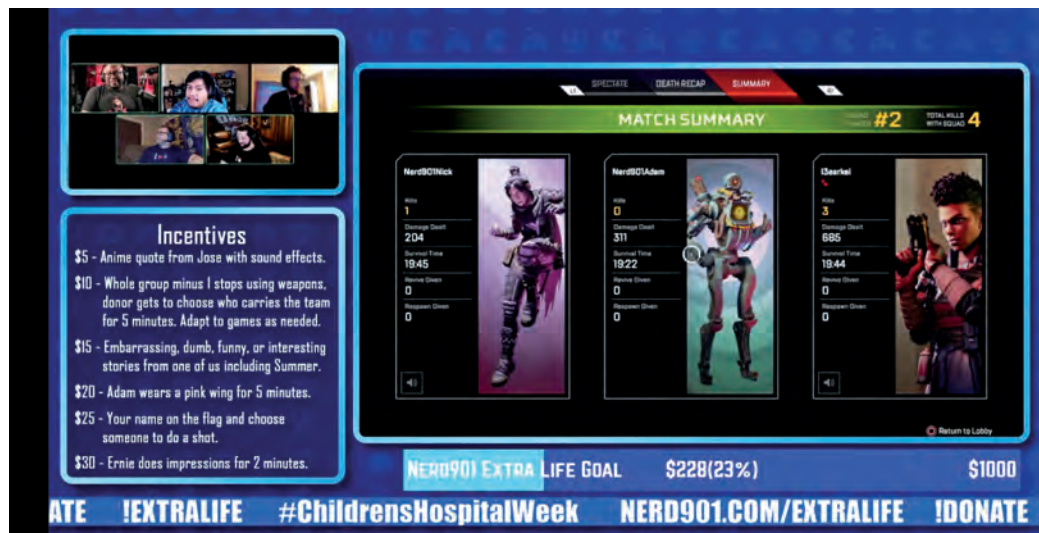
In one month, the Nerd901 team spread the word to their audience, rallied local sponsors from Old Dominick Distillery to New Wing Order, and jumped in.

With Paul's apartment as home base, Nerd901 streamed to their viewers for 24 hours straight, playing games and having fun. As guests tuned in,

cameras and color-changing lights.

Finally, in November, the day came.

At the \$4,000 mark, Nick had to dye his hair blonde.



This year's stream featured special guests that joined the Nerd901 team remotely to help raise money. Pictured here is Memphis 901 FC goalkeeper, Jim Barkeye, top right.

they could choose to donate, receiving everything from shout-outs onstream to sponsor gift cards in return. The team also spiced things up with higher-stakes donation rewards; three of the Nerd901 members had to eat ghost peppers live.

Nerd901 dived into their first Le Bonheur charity stream and came back up with \$2,600 in donations.

In 2019, the fundraiser leveled up.

The team jumped on planning, snagging a lineup of local personalities and donation prizes ranging from raffles for sponsor swag to Grizzlies tickets. A sympathetic donor loaned top-of-the-line tech for the stream, offering mics,

Donors breezed past \$5,000, scoring a secret goal: an after party at Rec Room, where a small cover charge per guest raised \$800.

The 2019 grand total: \$6,025.

"It's funny, because sometimes nerd culture can be viewed as toxic. But when it comes down to it, our audience really has a giving spirit," says Nick.

Last September, Nerd901 also held a game day in the Le Bonheur family room, playing MarioKart and Super Smash Bros with gamers big and small.

"We had kids ranging from 8 to 17 playing video games with us," says Adam. "We found out afterwards that



Keep up with Nerd901 at www.nerd901.com!

To learn more about Extra Life or to start your own fundraiser check out www.extra-life.org. Register solo or as a team, pick a day to play, set a goal and get the word out to friends and family!

some of the older kids, especially, said they really appreciated that.”

Siblings and parents dropped in, too.

Nerd901 plans to keep inspiring their community with the power of play. Not even COVID-19 could keep them from continuing this year’s Extra Life stream.

In six hours, they raised money for

“COVID-19 forced us to do everything remotely, but showed us how we can continue to stream and raise money for a good cause during these tested times. More than anything, we just want to thank the angels who donate.”

Nick Schifani

the hospital with special guests joining for the stream including Jim Barkeye, goalkeeper for Memphis 901 FC, and

Dustin Starr, local celebrity wrestler and emcee of both the Memphis Grizzlies and Redbirds.

“COVID-19 forced us to do everything remotely, but showed us how we can continue to stream and raise money for a good cause during these tested times,” says Nick. “More than anything, we just want to thank the angels who donate.”



The Nerd 901 team supports Le Bonheur through a variety of ways including livestream gaming fundraisers and visiting hospital patients for gaming sessions. In 2019, they raised \$6,025 during one 24-hour gaming livestream. Pictured above is the Nerd901 team - Nick Schifani, Adam Schifani, Ernie Carothers, Kevin White and Jose Garcia (back row, left to right) with Paul Schifani, Katee Forbis and Sean White (front row, left to right).



Giving Support, Sharing Knowledge

*Son's TSC diagnosis leads to innovative procedures
and opportunities to give back*

When Greyson Schwaigert was 6 months old, his parents Ryan and Brittany saw an ultrasound with cysts that looked like popcorn crowding their son's kidneys. Greyson was born with the genetic condition tuberous sclerosis complex

(TSC) type 2. That diagnosis led to polycystic kidney disease (PKD), an autism diagnosis and a long road of doctor's appointments, procedures and hospital visits.

Until recently, children with PKD like Greyson only had one option for managing cysts: an mTOR inhibitor

Above: Ryan, Lachlan, Greyson and Brittany Schwaigert

medication that slows the excessive cell growth leading to cysts and tumors. Now, surgeons can remove the cysts and keep them from returning, thanks to a new procedure developed by Le Bonheur Nephrologist John Bissler, MD.

Recognizing the value of the care and innovation available to their son in their home town, the Schwaigerts are dedicated to giving back to Le Bonheur and the families it serves.

AN INNOVATIVE PROCEDURE

Two distinct genes have been identified to cause TSC, and mutations in either gene can cause cells to divide excessively, causing lesions – including kidney cysts – throughout the body. These cysts eventually hamper the kidney’s ability to function properly.

Recently, Ryan and Brittany found themselves making a decision that could impact Greyson well into adulthood. Should they proceed with a new procedure that would drain many of the cysts from his kidneys?

“The option for this procedure took us by surprise, but we knew we wanted to be as aggressive as possible,” said Brittany. “It was also important to address this pre-puberty before it would become more difficult to control.”

Bissler joined Medical Director of Robotic Surgery Joseph Gleason, MD, to develop a procedure to “de-roof” or decorticate, kidney cysts to drain fluid, relieve pressure and prevent cysts from returning. The ultimate goal of successful kidney cyst decortication is prolonging kidney function to delay the need for kidney transplant. In addition, the procedure lowers blood pressure and improves balance and movement.

During the procedure, Gleason removed 800 mL of fluid from Greyson’s abdomen. The change was visible and immediate as they watched Greyson’s stomach deflate and blood pressure drop when they began to drain cysts.

The Schwaigerts were back home the same day as surgery and Greyson was back to his normal self within 72 hours of surgery. Bissler has since cut his blood pressure medication in half.

“With Dr. Gleason’s reputation and role as chief



Robotic Surgeon Joseph Gleason, MD, (middle) and Nephrologist John Bissler, MD, (right) confer before conducting a kidney cyst decortication procedure. Together, they have created a new procedure to treat polycystic kidney disease for kids like Greyson Schwaigert.

of robotics and our implicit trust in Dr. Bissler a world-renowned nephrologist, we knew we had a dream team,” said Brittany. “We’ve lived Greyson’s whole life with PKD as a weight upon us. It’s a relief that we no longer have to worry about the immediate risks of his kidney cysts.”

SHARING EXPERIENCES AND KNOWLEDGE

Through all of their experiences, the Schwaigerts have accumulated a wealth of knowledge – of a TSC diagnosis but also of the stresses and difficulties for families who spend time at Le Bonheur.

“We wanted to give others the support that we didn’t have when Greyson was diagnosed,” said Brittany. “Sometimes you need someone to talk to who has been

through a scary procedure or a surgery who can hold your hand. Other times you just need to know where to park.”

They are part of Le Bonheur’s Family Partners Council (FPC) – a group of parents dedicated to improving Le Bonheur’s care for children and families with the unique perspective of parents who

have been through it all. This group provides direction on everything from menu options for children to what kind of wording to use in the event of a child’s passing.

“If you’re only hearing the positives, you aren’t growing,”

“We wanted to give others the support that we didn’t have when Greyson was diagnosed. Sometimes you need someone to talk to who has been through a scary procedure or a surgery who can hold your hand. Other times you just need to know where to park.”

Le Bonheur mom, Brittany Schwaigert

says Ryan. “We get to review every portion of the hospital and give feedback. We feel heard.”

In fact, their experience with Greyson changed Le Bonheur’s IV and anesthesia induction policy for children with sensory processing difficulties. Greyson has frequent MRIs and requires sedation. However, he was not being sedated before the IV was given leading to some difficult and traumatic IV sticks.

After retired Le Bonheur President Meri Armour heard them discussing the issue at FPC, the Schwaigerts were meeting with the chief of anesthesiology within a week. As a result, protocols for patients with sensory difficulties changed rapidly – and Greyson could begin sedation before his difficult IV sticks.

They also find ways to involve their younger son, Lachlan, and have taught him early the value of giving back. He plays with other kids, both healthy and with medical conditions, during FPC meetings. He also helps his mom deliver boxes for the Confetti Foundation – a “birthday in a box” for children spending their special day in the hospital.

“Lachlan loves to deliver birthday boxes because he knows what it’s like to be in the hospital,” says Brittany. “It’s important to us that we expose him to kids who are different than him and to teach him the value of helping others.”



Greyson and Lachlan Schwaigert prepare to give the “birthday in a box” to children at Le Bonheur spending their special day in the hospital.

“After five years of being non-verbal, all of the work, treatment and therapy started allowing Greyson’s personality to peek through. It wouldn’t have been possible without the help of Le Bonheur.”

Ryan Schwaigert



Thanks to Nephrologist Dr. John Bissler, Ryan and Brittany Schwaigert no longer have to worry about the immediate risks of Greyson’s kidney cysts thanks to a new innovative procedure.

HELPING TSC FAMILIES

Close to heart for Brittany and Ryan is working with families whose children share Greyson’s TSC diagnosis. Brittany is the Le Bonheur ambassador to the TSC Alliance – a position which includes everything from talking to newly diagnosed families to organizing fundraising walks for TSC.

“Through the TSC Alliance, we talk to families about their questions from surgery and medications to non-medical needs like staying at FedExFamilyHouse, kid-friendly activities in Memphis and where to grab lunch,” says Brittany. “We take pride in Le Bonheur’s TSC clinic, and we have a dedicated group of families who want to connect.”

Brittany is also an administrator of a TSC Facebook mother’s group – what started with 10 members has now grown to more than 2,500. And the Schwaigerts are always looking for ways to extend support to any newly diagnosed TSC families in need.

Thanks to innovation at Le Bonheur like Greyson’s kidney cyst procedure, options are available for treatment that the Schwaigerts would never have dreamed possible.

“Le Bonheur, its Tuberous Sclerosis Clinic and amazing physicians like [Neuroscience

Institute Co-director] Dr. Jim Wheless have been so instrumental in giving us our son,” said Ryan. “After five years of being non-verbal, all of the work, treatment and therapy started allowing Greyson’s personality to peek through. It wouldn’t have been possible without the help of Le Bonheur.”

While Greyson’s journey with TSC will be lifelong, they are grateful for the immense strides in Greyson’s health that have been possible thanks to Dr. Bissler, Dr. Gleason, their research and their desire to pioneer new treatments and procedures.

“We’re donating our time, but we get so much out of it because we’ve been there as those scared, exhausted parents,” says Brittany. “Whatever you can give to an incredible institution like Le Bonheur – your money can’t go anywhere better.”



Recent Events

Jagathon

On Feb. 28, Desoto Central High School held its annual Jagathon Dance Marathon to raise more than \$12,000 for Children's Miracle Network Hospitals benefiting Le Bonheur. More than 175 students danced for six hours – a huge thank you to everyone involved!



Dance Marathon

Dancing together for five hours, 235 students at Mississippi State University came together to raise more than \$71,000 for Le Bonheur with their annual Dance Marathon. Thank you Mississippi State students who helped make this year's StateDM a success!

Memphis GenerosiTEA Party

This annual mom and daughter event featuring a fashion show, crafts and a tea party raised more than \$31,000 for Le Bonheur! Organized by a group of moms who want to help Le Bonheur help families, on Feb. 1 they held their 11th annual event with more than 400 people in attendance. The generosity of attendees provides funds for everything from purchasing therapy equipment for Le Bonheur's rehabilitation programs to providing a play space in the upcoming cardiovascular intensive care unit expansion.



West Tennessee GenerosiTEA Party

What could make for a better day than a fashion show and tea party! Recently, West Tennessee also held its GenerosiTEA Party on Feb. 29 for the fourth year running. Two hundred guests came together to raise more than \$15,000 for Le Bonheur.

The event included former Miss Tennessee Christine Williamson as emcee of the event and a fashion show along with crafts, photo booth, silent auction and plenty of delicious food.



You are the heart of Le Bonheur.

Thank you for keeping our heart strong.

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