

BILINGUAL EDITION 2021

'Cancer, I'm not scared of you'

St. Jude gave Mariángeles hope

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ST. JUDE INSPICE BILINGUAL EDITION 2021

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hew, six-year, \$11.5 billion strategic plan was recently announced for St. Jude Children's Research Hospital. The size and scope of its goals are extraordinary and will launch the research and treatment of catastrophic pediatric diseases to new heights, allowing us to reach our arms further around the world than ever before.

Among the plan's aims: unlock the secrets of several difficult-to-treat pediatric cancers that most often are fatal; increase the number of patients on St. Jude-led protocols may grow as much as 30 percent; build on the already audacious goals of St. Jude Global by tripling the investment by committing more than \$470 million over six years; and earmarking more than \$1.9 billion for campus-wide construction, renovation and capital needs..

It's an inspiring vision set on course more than 60 years ago by Danny Thomas, a visionary and innovator with a bold imagination.

Danny's dream was extraordinary in its impact, yet elegant in its simplicity: No child should die in the dawn of life. The means to that end, however, is anything but simple as we see in the complex road map drawn for the next six years. So we measure it a milestone at a time. A birthday. First steps. First bike ride. Driver's license. Graduations.

At St. Jude, we revere the opportunity for education. It's why the St. Jude School Program by Chili's is so crucial. It allows patients to keep up with their peers as they go through treatment. And it allows a sense of normalcy to infuse days of chemotherapy, physical therapy and doctors' visits.



Sixty years ago, these patients wouldn't have had the chance to study, much less graduate and dream of a career. The increased survival rate – 20 percent overall when St. Jude opened to more than 80 percent today – is a big part of that. Equally as important is the quality of life during and after treatment.

Improved quality of life is another goal of the St. Jude strategic plan. Through St. Jude LIFE Study, data from 6,000 childhood cancer survivors is being used with fewer long-lasting side effects. These programs will be part of a \$3.7 billion investment expanding cancer-focused research and related clinical care.

As quality of life improves, so does kids' development, allowing a fighting chance when it comes not just to surviving, but to fully living.

You, our incredible supporters, make this all possible. Thank you.

Richard C. Shadyac Jr. President and Chief Executive Officer, ALSAC @RickShadyac







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You can help ensure families never receive a bill from St. Jude for treatment, travel, housing or food. **stjude.org/donate**

YAMILA GAINS HER STRENGTH FROM HER HEART

NINE YEARS AFTER A LONG SERIES OF CANCER TREATMENTS BEGAN, YAMILA CONTINUES TO LEAD A LIFE FULL OF JOY.

St. Jude patient Yamila pictured during treatment in 2012.

Yamila and her parents were interviewed at St. Jude while she was undergoing treatment.

Yamila: My name is Yamila, I am 9 years old and I'm a patient at St. Jude. I gain my strength from my heart and from everyone who loves me.

Mom Yahaira: Yamila is a very cheerful girl, she's a girl with a great heart. A girl who's really alert, really attentive, always with a great zest for life.

After multiple attempts to cure her acute lymphoblastic leukemia in Puerto Rico, Yamila was transferred to St. Jude to begin lifesaving treatment. **Mom:** My only wish is to see her grow up, I just want her to be healthy. For her to be a true heroine in this battle.

At age 6, Yamila received a bone marrow transplant, but less than three years later, the leukemia returned and she had to undergo a second bone marrow transplant.

Dad Rafael: She has had a few relapses, but we have not let ourselves be defeated. Nor will we let ourselves be defeated. We will always come out victorious.

Mom: Just two days after the treatment, and she was the same little happy girl she's always been. I feel completely certain that in this

instance, the treatment worked.

Today, Yamila is 15 years old and cancer free.

Dad: For myself and my family, St. Jude means life!

Mom: She's going to have a future, I know that she's going to have a future.

Dad: When I look into Yamila's eyes, I see something wonderful, something full of life, I see... strength. I see a love for everyone... for life.

Mom: To know that she's healthy helps us realize that nothing else matters.

A St. Jude mother's resolve:



It has been 20 years since Mariangeles Grear was cured of childhood cancer. It was her mother's voice that carried her through.

Kristina Goetz - ALSAC



ariangeles Grear was 13 years old, lying in a hospital bed at St. Jude

Children's Research Hospital so near death there was a chance she might not wake from a coma.

It wasn't the acute myeloid leukemia that was killing her at the moment. It was an infection doctors couldn't find. It may have reached her brain, they said. And no medication was working to stop it.

Mariangela Rubio, Mariangeles' mother, refused to let her daughter surrender.

Mi amor, she said. Despierta. Regresa a mí.

My love. Wake up. Come back to me.

She prayed the rosary and asked God and the Virgin Mary to heal her daughter.

She's ashamed of how much she cried in those days. But she never wavered over whether her daughter would live. Not once.

"I believe in the Lord and St. Jude," Mariangela said. "Every problem has a solution."



This year marks 20 years since Mariangeles was cured of AML, a type of blood and bone marrow cancer. And it's been her mother's voice – uncompromising, unwavering, unrelenting – that has seen her through all those years. The cancer. Two hip replacements. And now infertility.

"My mom is my rock through everything in life," Mariangeles said. "She is the reason I could look cancer in the face: I'm not scared of you because you should be scared of my mom.

"If you think you're coming for me, you better think twice because of that red lipstick over there."

A deadly diagnosis

It was September 2000 in Maracaibo, Venezuela, when Mariangeles fell ill with a mysterious sickness. Her gums were so swollen her teeth seemed to disappear. Purple and yellow bruises covered her body. And her fever was, at times, so high that even her eyelids burned.

Her pain was in both flesh and bone.

"I have no power in my body," she told her mother.

It was the only way she could describe how she felt.

Even Mariangeles' father, a doctor, didn't know what was wrong with their daughter.

After many tests, a hematologist at a private hospital delivered devastating news: Mariangeles had advanced cancer and needed an immediate bone marrow



transplant. And that wasn't possible in Venezuela.

Without one, the doctor said, she might only have five days to live.

Mariangeles' father wept.

As a doctor, he knew her condition was grave. He was resigned to find

Mariangeles a comfortable room in the clinic to spend her last days.

But Mariangeles' mother was defiant. She demanded to see the paperwork.

"Who are you to tell me my daughter will die in five days?" she told the doctor. "She is not going to die." The doctor suggested the family travel to Italy or Cuba. Maybe the United States.

There was this place in Memphis called St. Jude. The doctor would refer her to see if she could be treated there.

Mariangela had been a high-ranking official under former Venezuelan President Rafael Caldera. She'd traveled the world – to Italy, Colombia, the United States. But always to New York or Miami.

The only thing she knew about Memphis: It was the city where Elvis was from.

Hope in the patron saint of lost causes

In a matter of days, Mariangeles and her parents arrived in Memphis, before the marble statue of St. Jude Thaddeus at the entrance of the hospital. *Patrón de las causas perdidas*, her mother thought. The patron saint of lost causes.

"*Mi amor*, my love – this hospital – you're going to have no more problems here," she said.

Mariangeles didn't need a bone marrow transplant after all, only chemotherapy.

But the next nine days would prove to be the most tormenting of her mother's life.

The chemo Mariangeles was given the first day was working. But the fungal infection would not abate. Mariangeles' lungs were filling with fluid. Doctors induced a coma. She was put on a ventilator.



Mariangela never left the room.

In the haze of the coma, Mariangeles recognized the sound of the automatic doors- fooffhh - the yellow protective gear that turned nurses into astronauts, and her mother's ever-present voice. Pleading for her to be strong, to come back.

Creer en San Judas. Creer en el Señor. Creer en ti mismo.

Believe in St. Jude. Believe in the Lord. Believe in yourself.

Doctors offered to try a new medicine, and Mariangeles' parents agreed. It worked. But even as the doctors weaned her from the induced coma, she did not wake up.

Still, her mother refused to give in. Her daughter would not die.

She kept talking. Praying the rosary. Calling Mariangeles' name.

On the ninth day, Mariangeles called out – garbled – over the tube in her mouth:

Mami?

WHO ARE YOU TO TELL ME MY DAUGHTER WILL DIE IN FIVE DAYS? SHE IS NOT GOING TO DIE.

- Mother of Mariángeles

The first face she saw was her mother's – coal black hair perched in an updo and her signature red lipstick, Velvet No. 37.

The only way to explain it, Mariangela said, was that her daughter was a miracle.

Fighting for health, searching for beauty

For the next six months, Mariangeles endured five rounds of chemo. She lost weight. Her skin turned dark. And she threw up almost every day.

"If you can just go to sleep and die, it will stop," Mariangeles remembered thinking. "That's why people give up. The pain is indescribable."

But her mother told her to eat when she didn't feel like it. Said to hold on when things got hard. Told her to believe God had a mission for her life.

Even when Mariangeles woke to clumps of hair on her pillow – once long and full like the Miss Venezuela contestants she so admired – her mother did not abide sulking. The hair would grow back.

In the meantime, they'd buy dangly earrings, pink caps – and lipstick.

"She was saying: 'We can make you beautiful without hair,'" Mariangeles said.

Every problem has a solution.

Mariangeles' dad had to go back to Venezuela four months into her treatment – to his medical clinic and to Mariangeles' other siblings. But her mother never left her side.

And just six days before her 14th birthday, Mariangeles was declared cancer free.

"Everything I went through, she was there."

A life to live, a dream to catch

After treatment, Mariangeles' mother got a government job in Memphis so she stayed in the United States. Mariangeles went back to Venezuela for a year with her dad but came back to St. Jude every three months for check-ups. When she developed a polyp in her nose, her mother decided Mariangeles needed to be close to the hospital, in case anything else went wrong.

So Mariangeles moved to Memphis for good.

She grew her hair out again and didn't cut it for five years. Long, thick locks tumbled down her back again, just like the Miss Venezuela contestants.

She graduated high school, then college and went on to work in national, big-name firms in business development. She was grateful to St. Jude for saving her life but wanted to put cancer behind her. She didn't tell people she was a cancer survivor, never brought it up in job interviews or in meet-ups with new friends. She kept that part of her story to herself.

She was reluctant to tell even her now-husband, Matthew Grear, for fear he might pity her.

It wasn't until 2017 when she joined ALSAC, the fundraising

and awareness organization for St. Jude, as a development specialist that she started to feel comfortable telling her own story.

Long before she spoke publicly, she had been part of St. Jude LIFE, a research study that brings former cancer patients back to campus for regular health screenings.

Now, that decision may well shape her dream to come.

Devastating news

In April 2019, Mariangeles was in the Dallas airport, waiting for a connecting flight when she got a call from her OB-GYN with some distressing news: Tests showed she was pre-menopausal and had the eggs of an older woman.

Mariangeles was only 31.

There was no way to know why this was happening. Many factors affect fertility. But there was no time to waste. The OB-GYN had already made her an appointment with a prominent fertility specialist in Memphis. But that was four months away.

Mariangeles wept.

The young girl who had collected dolls, the one who treated her siblings as if they were her own children might not be able to have a baby of her own.

"We always have this joke: We're Catholic. It's in the wine," Mariangeles said.

But what if that was not to be?

Mariangeles called her mother,

inconsolable about the heartache that might come.

The voice on the other end of the line was having none of it.

"Did she tell you that you couldn't have kids?"

No.

"Then wait until they tell you that."

Every problem has a solution.

That week, Mariangeles was at her St. Jude LIFE appointment when she broke down, sobbing. She told the nurses and her social worker about the fertility test results.

Two days later she was referred to the St. Jude fertility clinic for a consultation with doctors.

"Come to find out, God had a bigger plan," Mariangeles said.

The doctor who walked in was the same specialist her OB-GYN said would take four months to see.

How about the following Monday? Could her husband come to see him then?

Yes. It was her birthday.

Since then, Mariangeles has gone through three rounds of artificial insemination, which were unsuccessful.

But in February, she began hormone treatments at a private fertility clinic for in vitro fertilization – thanks to the consulting doctor who's known as a leading fertility specialist in Memphis.

All because of St. Jude.

"Three years ago I was crying in an airport because ... I was not gonna

be able to have a kid," Mariangeles said. "And today I sit back and reflect how St. Jude has, once again, given me that hope. They connected me to the doctor. They got me into the best doctor in Memphis."

For Mariangeles, the dream of a family seems so close.

"I know I can't get ahead, but I close my eyes and see myself at that first (ultrasound) when you can hear the heartbeat," she said. "Or if it's a daughter, going to buy all the bows that I can find in the world.

"She will be my real-life baby doll. I will play dress up with her. And if it's a boy, let's go get a bat because you're going to be the next baseball player because that's what my dad did."

But then she hears her mother's voice. There is no doubt.

"Mariangeles will have a baby this year," her mother said. "Believe me."

Every problem has a solution.







ST. JUDE CHILDREN'S RESEARCH HOSPITAL TO INVEST \$11.5 BILLION TARGETING CHILDHOOD CATASTROPHIC DISEASES GLOBALLY



Photo was taken prior to the COVID-19 pandemic.



t. Jude Children's Research Hospital is launching the largest strategic expansion in its nearly 60-year history,

investing more than \$11.5 billion over six years to accelerate research and treatment for children around the globe with catastrophic diseases.

The six-year plan was adopted in March by the St. Jude Board of Governors. Most of the \$11.5 billion plan will be funded by donors and require no debt.

"We're committing substantial resources to broaden scientific understanding, raise survival rates, improve quality of life, and connect researchers worldwide in the quest to find cures and save children with cancer and other deadly diseases," said James R. Downing, M.D., St. Jude president and CEO.

This roadmap builds on the prior six-year St. Jude strategic plan, which at the time was the largest for the institution and resulted in \$7 billion in investment. During that period, St. Jude accepted 20 percent more new cancer patients; increased faculty by 30 percent and staff by 23 percent; and embarked on several largescale construction projects, including the recently opened \$412 million Advanced Research Center.

And, significantly, it also began building the global infrastructure required to provide access to quality care to children in low- and middle-income countries through accelerated international outreach efforts.

This newest six-year plan focuses on the expansion of patient care and clinical and laboratory-based research related to pediatric catastrophic diseases, including work in cancer, blood disorders, neurological and infectious diseases. It adds 1,400 employees, 70 of them faculty positions.

E THE PLAN HIGHLIGHTS

\$1.9 BILLION IN Capital spending.

Among the construction projects: a proposed, \$585 million outpatient clinic and doctors' office; and a new \$110 million patient family housing facility.



MORE THAN \$1 BILLION TO EXPAND RESEARCH IN NONMALIGNANT DISEASES.

The \$1.1-billion investment will expand and accelerate research into sickle cell disease and other blood disorders; create a new laboratory-based research program in infectious diseases that affect children worldwide; and establish a new research and clinical program to better understand and treat pediatric neurological diseases.

\$3.7 BILLION INVESTMENT TO EXPAND CANCER-Focused Research And Related Clinical Care.

The key areas of focus include cancers with the lowest survival rates and improving quality of life.

The cure rate for childhood cancer has increased from 20 percent overall when St. Jude was founded in 1962 to 80 percent today due in large part to the research and treatment conducted at St. Jude. But researchers have yet to unlock the secrets of several difficult-totreat pediatric cancers that most often are fatal.

Under the new plan, St. Jude will increase investment into uncovering why cancers arise, spread and resist treatment. This includes hiring more researchers dedicated to advancing insights across the spectrum of pediatric cancer–leukemia, solid tumors and brain tumors–and cancer subtypes.

The number of patients on St. Judeled protocols may grow as much as 30 percent. Those numbers are achieved through a small increase in patients admitted, and through an increase in multi-institutional studies. St. Jude already leads trials on medulloblastoma, for example, at 16 other institutions in four countries.

With survival rates for childhood cancer steadily rising, researchers increasingly have focused on advances that also improve the quality of life for patients. St. Jude has led the way in developing less-toxic treatments that reduce the risk of devastating and long-lasting side effects from chemotherapy and radiation, but there's still tremendous progress to be made.

As part of its research, St. Jude has amassed critical historical data by following more than 6,000 childhood cancer survivors as they age.

ST. JUDE WILL MORE THAN TRIPLE ITS GLOBAL INVESTMENT TO IMPROVE SURVIVAL RATES AROUND THE WORLD.

In 2016, St. Jude expanded its global efforts through the development of St. Jude Global and the St. Jude Global Alliance. The goal was to mobilize caregivers, foundations, and governments to work collaboratively toward developing the workforce, healthcare systems, and research expertise required to address the growing worldwide childhood cancer burden.

In 2018, St. Jude expanded its efforts through a \$15 million collaboration with the World Health Organization called the Global Childhood Cancer Initiative. The goal of the effort was to raise survival rates in low- and middle-income countries for children with the six most common forms of cancer from 20% to 60% by 2030.

This new plan builds on the work by tripling St. Jude's investment – committing more than \$470 million over the six-year period. Major efforts under this expansion include:

- Development of a multimilliondollar Pediatric Cancer Global Drug Access Program – in collaboration with WHO, other U.N. agencies and international organizations – to distribute an uninterrupted supply of anti-cancer drugs for childhood cancer treatment in low- and middle-income countries.
- Expansion of educational programs to train the workforce needed to treat childhood cancer worldwide.
- Creation of seven international operational hubs staffed by St. Jude workers to effectively manage the St. Jude Global Alliance, a network of more than 140 institutions across 50-plus countries.

Responsibility to fund the historic expansion falls to American Lebanese Syrian Associated



Charities (ALSAC), the fundraising and awareness organization for St. Jude. Under a unique operating model in place since Danny Thomas founded St. Jude, it's able to focus exclusively on treatment and research because ALSAC, also founded by Thomas and headquartered on the same Memphis campus, works with millions of donors to raise the money to make the mission possible.

Private fundraising conducted by ALSAC is the organization's lifeline because pediatric cancer research typically receives a disproportionately low share of government research dollars. Of the approximately \$6 billion distributed annually by the National Cancer Institute, for example, only an estimated 4% targets pediatric cancers.

As a result, it is projected that 87% of funds to sustain and grow St. Jude over the next six years will come from public donations and investment income.

ALSAC partners with more than 11 million active donors who give to fund most of the \$1 billion-plus cost to operate St. Jude annually as well as fund its capital projects.



HAYLEY ARCENEAUX:

What the Inspiration4 mission for St. Jude means to me

Hayley Arceneaux, a pediatric cancer survivor, will be part of the world's first all-civilian space crew on Inspiration4 later this year. She talks about the meaning behind the mission, which will raise money and awareness for St. Jude Children's Research Hospital, the place that saved her life and where she now works as a physician assistant.



Imagine being a 9-year-old girl, visiting NASA on a family vacation, falling in love with space and the wonders of exploration.

That was me, just a few months before I found out I had osteosarcoma – bone cancer – and was bound for St. Jude Children's Research Hospital.

I remember pretending to be angry as we arrived, but in reality, I was just so scared. At the time, cancer to me seemed like a death sentence because everyone I had known who had it passed away.

As soon I entered the doors of St. Jude, however, I felt hope, a sense of optimism that I could get through this. SPIRATIA

That's why I'm so grateful to be a part of Inspiration4, the world's first all-civilian mission to orbit space.

Because the mission supports St. Jude, the amazing place that saved my life, and where I've returned to work in my dream job as a physician assistant.

And especially because of the message it sends to the kids of St. Jude, like the leukemia and lymphoma patients I work with every day – that a cancer survivor can do things they never dreamed possible. A cancer survivor can even go to space.

That's what happens when people support this historic mission. They're supporting the healing mission of St. Jude, to find cures for catastrophic diseases, and to treat some of the sickest children in the world, regardless of race or creed or their family's ability to pay.

But St. Jude doesn't just save lives. It changes them. I'm living proof. Being at St. Jude as a patient made me want to come back and work there. I wanted to be a part of that incredibly hopeful environment. I wanted to share the love that my family and I felt.

That day came last year, when St. Jude offered me a job as a physician assistant. It was the happiest moment of my entire life.

Cancer, and St. Jude, shaped me in other ways, as well. Because I was given a second chance, I wanted to make every day count. Maybe that's why I grew up to have such an adventurous spirit. I developed a love of travel, especially to other countries. Somehow, I feel most alive when I'm immersed in other cultures, enjoying new foods and



hearing different languages.

I had planned to visit all the continents by the time I turn 30, which is later this year. The COVID-19 pandemic put that goal out of reach.

Enter Inspiration4. When I first heard about the mission and was asked if I would like to go to space, I could scarcely answer fast enough. "Yes, yes, thank you," I said. "Please send me to space." While on Inspiration4, I'll be riding in the seat representing the mission pillar of Hope. It's one of two seats, of the total of four. dedicated to St. Jude. I can't say enough about the commander of the mission, Jared Isaacman, the founder and CEO of Shift4 Payments, who's an accomplished pilot in his own right, as well as a generous, down-to-earth leader.

Since signing on to the mission, I've been to the SpaceX complex in California to get fitted for my seat and my astronaut suit – which, if you can believe it, involved 220 measurements – and tour the facilities.

And did I mention I'm the first astronaut with an internal prosthesis? That's more than just a source of personal pride. I hope to show how barriers to space travel are falling away. And as a survivor of childhood cancer, I particularly want to inspire my patients back at St. Jude, proving to them that not even the sky should be the limit to their dreams.

(4) N

So while I won't be able to visit all the continents before I turn 30, I will be circling the globe every 90 minutes during the Inspiration4 mission, and raising awareness for the St. Jude mission along the way.

As an avid adventurist making the most of my second-chance life, I can't think of a more thrilling way to see the world.

Dedicated Hispanic donor makes St. Jude part of her legacy

In one final act of giving, Lydia de la Cuesta is leaving the children of St. Jude in her will.

By Andrea Suels and Kerry Healy ALSAC



ydia de la Cuesta lost her only son, Gustavo, to cancer five years ago. She got 54 birthdays with him.

Not nearly long enough.

He battled pancreatic and kidney cancer, which later spread to his lungs and brain. Despite an initial six-month prognosis, his illness lasted for a year and a half. Gustavo had a daughter and a son, and was a grandfather of two.

"He was the light of my life, and now that I have experienced what some St. Jude mothers go through, I thank God for all the moments we were able to share with him," said Lydia.

Lydia cherishes many memories with her son: road trips, dining out, watching basketball games together on TV. They shared a deep empathy for the families of St. Jude, especially after Gustavo started his cancer treatment as an adult. "He had a generous heart and was willing to help anyone in need."

With a low-wage job and a mountain of medical bills from his first visit to the emergency room, Gustavo's compassion for the children at St. Jude grew even more. Lydia fondly recalled a time when they were both watching a St. Jude commercial on TV and her son teared up, asking her, "Mami, why do those children have to suffer so much? Did you send the money to St. Jude yet?"

Born in Havana, Cuba, Lydia immigrated with her family to the United States at 28. After living several years between Puerto Rico and Florida, Lydia and her family settled in Miami, where she had a career as an accountant. She started donating to St. Jude more than 20 years ago. "I felt so sorry for these young children who had to go through such an unpleasant illness," she said. Throughout the years, Lydia kept her commitment to St. Jude, even when her financial situation was less certain.

In 2017, Lydia made it known she wished to include a gift to St. Jude in her will to create a lasting legacy for her family. "It is a sacrifice made by all who are working at St. Jude and those who donate to the organization," she said. "At St. Jude, they do help the children and I know the money will be well used."



To learn more about how you can create a legacy with St. Jude, call us at (800) 395-1087 or email us at giftplanning@stjude.org. **Bilingual Edition 2021**



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