



Spring 2020 | Phoenix Children's Hospital Foundation

HOPES & DREAMS

DISCOVERY AND INNOVATION

Accelerating breakthroughs into the next decade



Teresa and Raymundo Parrasmundo at Phoenix Children's. Read their story on page 8.

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INSIDE THIS ISSUE

- 04** Letter from Steve
- 05** The Future Is Within Reach
- 06** Fostering Discovery:
Bringing the Future of Cancer
Treatment to Phoenix
- 08** The Gift of Life:
Teresa and Raymundo Parrasmundo
- 10** **The Ghiz Family:**
Helping Phoenix Children's
Discover a Cure
- 12** Driving Innovation:
Transforming Medicine
With the Power of Data
- 14** **Joan and Larry Jarnigan:**
Investing in the Future
of Heart Care
- 16** **NextPhase Enterprises:**
A Family Business
Built to Serve
- 18** Signature Events:
Everyone Who Participates
Makes an Impact

Cover: Dr. Daxa Clarke (left) and Dr. Vinay Vaidya (right) review a digital data dashboard on Phoenix Children's patients diagnosed with pectus excavatum. Read the story on page 12.

Hopes & Dreams is published by the Phoenix Children's Hospital Foundation.
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DEAR FRIENDS:

These are unprecedented times.

As this situation has unfolded, I've found myself reflecting on how far we've come as a community, and how together, we can accomplish anything. One thing I know for sure: It is thanks to you and your enduring support that Phoenix Children's has become one of the most highly regarded health systems in the nation - and a place where families turn in times of extraordinary need.

Even as we confront one of the most challenging health crises of our times, I can't help but think that our culture of excellence is exactly what will see us through. I feel very fortunate to be a part of this organization at this time - as the science and medicine of pediatrics undergoes rapid and transformative advancement. At Phoenix Children's, we have become known for our consistent and enduring drive to be better as an organization and discover new and innovative ways of providing our children with the best that medicine has to offer.

As you will read in the pages that follow, our physician leaders are breaking new ground in so many ways. They are editing cells to attack cancer where it starts and put more patients in remission than we ever thought possible. Investments in supercomputers and data mining are revolutionizing our ability to predict life-threatening crises like sepsis, kidney toxicity and cardiac arrest - and prevent them before they happen. And using 3D technology, we are diagnosing and treating heart and brain disorders with a level of precision that was unimaginable just a decade ago.

At Phoenix Children's, we are one of the first hospitals in the country to translate these emerging capabilities into real solutions for children - solutions that will enable us to meet the challenges of today, while preparing for the crises of tomorrow. But the pursuit of excellence never ends. To stay at the forefront of pediatric medicine, we have to keep striving, keep reaching and keep pursuing the absolute best for our kids, every single day.

This issue of Hopes & Dreams tells the stories of the leaders spearheading groundbreaking work to meet medicine's most pressing challenges; the patients who are the living examples of their success; and the donors - like you - who are making all of this a reality.

Join us, and help Phoenix Children's continue to reach new heights.

Sincerely,



STEVE SCHNALL

Senior Vice President & Chief Development Officer



THE FUTURE IS WITHIN REACH

At Phoenix Children's Hospital, we are continuously striving to elevate our game for children in need. Thanks to your generosity, Phoenix Children's now stands on the precipice of becoming one of the top-10 pediatric hospitals in the country. Here are the bold steps that we are taking to get there.



Recruiting visionary physician leaders who will change the shape of medicine from right here in Phoenix



Establishing destination programs that will serve young patients from the Southwest and around the world



Fostering discovery that will improve the quality and length of children's lives



Driving innovations that will give ill and injured children hope beyond their wildest dreams

Read more about our plan to build world-class programs at Phoenix Children's Hospital by visiting phoenixchildrensfoundation.org/withinreach.



Dr. Roberta Adams,
Hematology and Oncology

FOSTERING DISCOVERY

BRINGING THE FUTURE
OF CANCER TREATMENT
TO PHOENIX

After all else fails, it's CAR-T to the rescue.

When CAR-T* cellular therapy hit the world of oncology, it was heralded as a revolutionary breakthrough in cancer treatment and a powerful last step when chemotherapy and other treatments have failed.

Traditional chemotherapy can be devastating to a patient's system, attacking tissue throughout the body – whether cancerous or healthy – and causing debilitating illness. Some cancers are also highly resistant to chemotherapy, leaving patients with minimal chances of a cure.

* CAR-T stands for Chimeric Antigen Receptor T Cells.

Enter CAR-T, a form of immunotherapy that genetically alters a patient's own cells to recognize, target and destroy *only* the cancerous cells, leaving healthy cells intact. Early evidence indicates that this approach not only minimizes side effects, but also has the potential to keep more patients in remission for longer.

Since CAR-T therapy gained FDA approval in 2017, a handful of hospitals across the country – including Phoenix Children's – were selected to enroll patients in the treatment. Given its excellent clinical outcomes, Phoenix Children's is now managing one of the largest cohorts of CAR-T patients nationally – treating more than 10% of all patients receiving the innovative new therapy in the United States.

“With CAR-T therapy, we are seeing remission rates as high as 90%.”

Phoenix Children's enrolls children with acute lymphoblastic leukemia (ALL), the most common type of childhood cancer. For Dr. Roberta Adams, the pediatric hematologist/oncologist leading the CAR-T program for Phoenix Children's, bringing such a groundbreaking treatment to ALL patients in Phoenix has been life-changing.

“With CAR-T therapy, we are seeing remission rates as high as 90%,” says Dr. Adams. “We are suddenly taking kids with a 10% chance of survival at best and putting 90% of them in remission. It's unbelievably exciting.”

The challenge is what happens in the months that follow. While 9 in 10 patients go into remission immediately after starting CAR-T, fewer than half of those patients remain in remission. Dr. Adams and her team – including Dr. Dana Salzberg – are now working to identify why that is and learn how to keep all children on CAR-T in remission.

Dr. Salzberg, who sees patients through from initial diagnosis to bone marrow transplantation, says the opportunity to discover new, less toxic and more effective ways of treating her patients has been extraordinary.

“CAR-T is about allowing kids to live their lives to the fullest,” says Dr. Salzberg. “For children who had a low chance of survival before this treatment, it gives them the ability to join the school band, compete in gymnastics, play soccer and go to college. It's the gift of life! But we still have a lot of work to do. We want to give that gift to every patient.”



**Dr. Dana Salzberg,
Hematology and
Oncology**

THE GIFT OF LIFE

TERESA AND RAYMUNDO PARRASMUNDO

When a child fights cancer, the entire family fights with them. Teresa Parrasmundo, who refused to give up on her son Raymundo, found another fighter who would not take no for an answer: Phoenix Children's Hospital.

It was Teresa's birthday when she learned that her 10-year-old son Raymundo was eligible for the Phoenix Children's CAR-T program. "I couldn't believe it," she said. "Anything like this had felt so out of reach. I will never forget that day."

Since being diagnosed with leukemia at age two, Raymundo had relapsed three times. But Teresa never stopped fighting. Even when her son was so sick that he couldn't eat; when life-threatening infections made him too weak to receive treatment; and when Raymundo was near death after months in the intensive care unit; even in those moments, Teresa felt hope.

"I don't give up," says Teresa. "I always tell him that *everything* is possible. And I kept looking at every option so my son could stay with us."

CAR-T is the next step when all other treatments fail, so Raymundo's history of relapse made him an ideal

candidate for the CAR-T program at Phoenix Children's and he was immediately enrolled. Within months of beginning the therapy, Raymundo had come back from the brink of death. For the first time, he was well enough to undergo a bone marrow transplant. And nearly one year later, mother and

"It is like my son was born again at Phoenix Children's."

son are celebrating more than 250 days in remission – a promising milestone.

"This is a kid who doesn't give up, and a mom who

doesn't say no," says Dr. Dana Salzberg. "Teresa has given her entire life for Raymundo. And because she found us, CAR-T put Raymundo in remission when nothing else worked."

Now 11, Raymundo's life is finally moving beyond his cancer diagnosis. He has his appetite back and more energy than ever. And he's looking forward to going back to school and maybe even playing soccer. Doctors say that if he continues to improve, he will be back in the classroom in a matter of months.

"It is like my son was born again at Phoenix Children's," says Teresa. "That place is a blessing."





Teresa and Raymundo
at Phoenix Children's.

WHY THEY GIVE

THE GHIZ FAMILY

Helping Phoenix Children's Discover a Cure

For the Ghiz family, giving back is a family affair.

Buzz and Janice Ghiz were both raised to give. Buzz's parents, who put down roots in Arizona in the 1940s and quickly became pillars of local business, taught their son that it was his responsibility to invest in the community and help it grow and thrive. When Buzz and Janice got married, began their own business and looked to carry on that legacy, they found themselves seeking a cause of their own.

Buzz says that he's not sure why Phoenix Children's compelled him the way it did. He had no personal connection to the Hospital. He just felt a profound sense of compassion for children in need. And that was enough.

Buzz and Janice's three children – Nick, Annalise and Anthony – grew up immersed in their parents' commitment to service, so much so that they saw Phoenix Children's as an extension of their own family. So when Nick Ghiz came of age, he found himself wanting to do more than just make an annual donation. He wanted to make an impact.

"We were raised to use our blessings to bless those who are less fortunate," says Nick. "And I just wanted to do something more tangible for Phoenix Children's. Something bigger."

The family learned that the Phoenix Children's Center for Cancer and Blood Disorders was looking to expand its clinical trials program to discover new and innovative ways of treating children facing harrowing diagnoses, and that there was an opportunity to support that work over the long-term.

"It just struck a chord," says Buzz. "The idea that we could help Phoenix Children's find a cure for cancer. We wanted to be a part of that."

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Phoenix Children's the resources it needed year after year to pursue a cure for cancer, but also connect their own family legacy to the Hospital for decades to come.

"It's so simple," Buzz says of the family's motivation. "It's coming together to help children go on to live wonderful, beautiful lives. End of story."

The entire family met to discuss the opportunity. They decided that together they would make a contribution that would fund clinical research at the Center for Cancer and Blood Disorders permanently – a gift that would not only give



At right: Clinical trials conducted by medical lab scientists like Kevin Nicholson (pictured) and supported by generous donors like the Ghiz family drive discovery at Phoenix Children's. At left: The Ghiz family. Left to right: Buzz, Janice, Nick, Annalise and Anthony.





DRIVING INNOVATION

TRANSFORMING MEDICINE WITH THE POWER OF DATA

For Dr. Vinay Vaidya, Chief Medical Information Officer at Phoenix Children's, creating a world-class hospital means harnessing the power of data.

Dr. Vaidya wasn't always in information technology. Before joining Phoenix Children's in 2009, he was a pediatric intensivist, treating critically ill patients in the intensive care unit (ICU) at the University of Maryland Medical Center. Dr. Vaidya loved his work. He found it deeply gratifying to help a child recover from a life-threatening illness.

But with the advent of electronic medical records, Dr. Vaidya became interested in clinical informatics – a data-driven approach to health care delivery. He began to experiment with creating simple computer

**“Data gives
our clinicians
superpowers!”**

programs to help himself and his fellow physicians quickly retrieve and interpret the vast streams of information generated on patients in the ICU. It didn't take long for Dr. Vaidya to realize that these tools were having a powerful impact – they were improving the quality of his own practice and helping other doctors provide better, more informed care.

“Clinical practice is in my DNA, but technology has helped me support the practices of so many other great physicians,” says Dr. Vaidya. “Now, instead of taking care of 20 to 25 patients, I'm using these tools to help care for hundreds of children who are in the Hospital right now.”

At Phoenix Children's, the transition from paper to electronic medical records was just the first step in a much bigger data revolution spearheaded by Dr. Vaidya, Dr. Daxa Clarke, Associate Chief Medical Information Officer and their team. Over the past

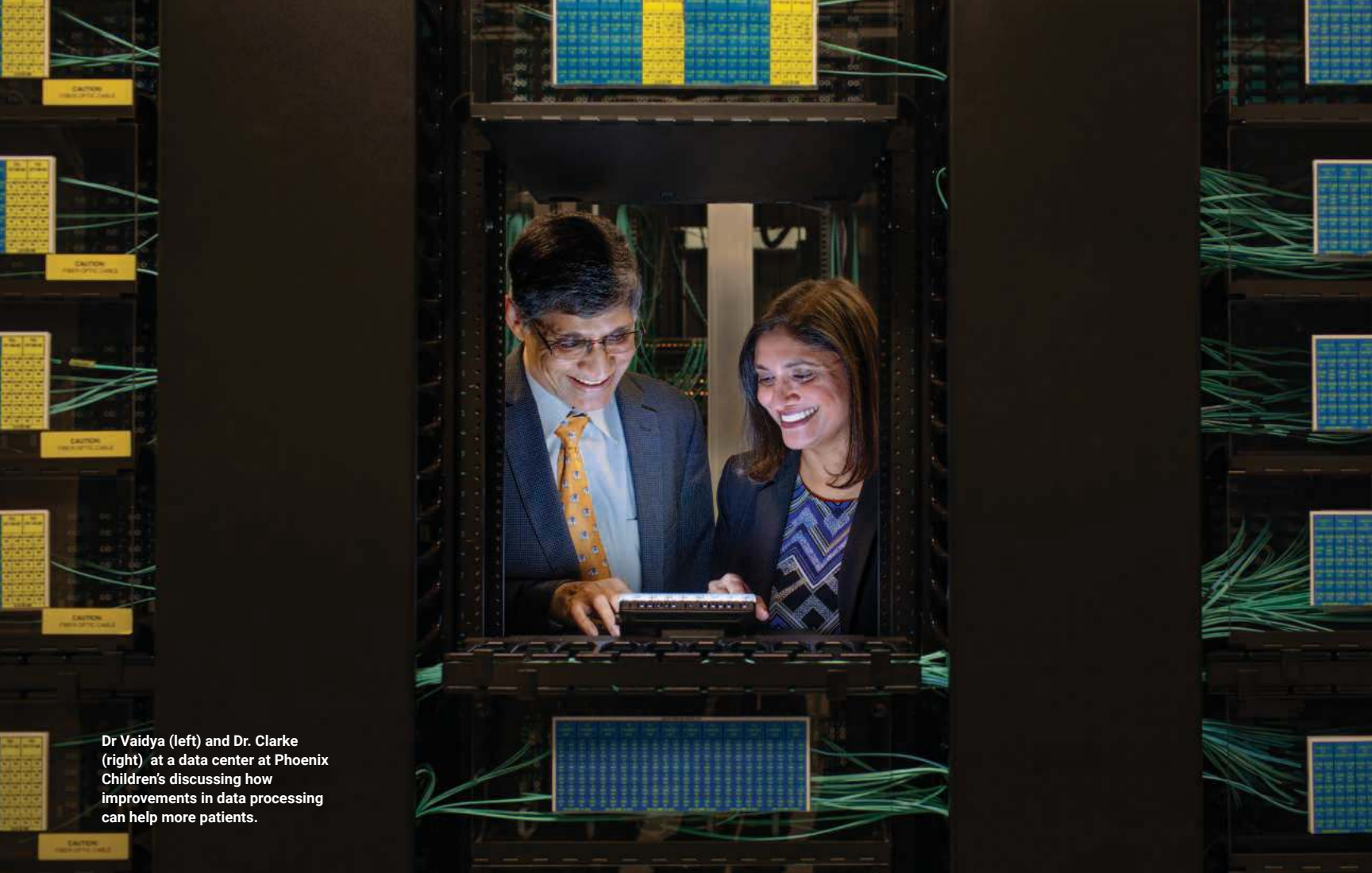
decade, information technologists at Phoenix Children's have undertaken a groundbreaking effort to put all that digital information to work in the form of electronic dashboards – user-friendly programs that aggregate and visualize patient data across hospital systems, disease profiles and populations.

Today, Phoenix Children's physicians are using these dashboards to unlock powerful insights into every facet of patient health – from how subtle adjustments in prescriptions can improve a patient's prognosis, to predicting the likelihood that a patient will suddenly experience a life-threatening event.

Consider a small child admitted to the Hospital for a ruptured appendix. During his stay, he suddenly develops an acute kidney infection so severe that his condition becomes critical – a situation that affects thousands of pediatric patients across the country every year. In the past, there would have been no way to predict such an event. Today, doctors at Phoenix Children's can not only predict kidney injury, they can prevent it.

Drawing on the clinicians' knowledge of kidney toxicity and the technologists' expertise with big data, Dr. Vaidya's team developed a user-friendly kidney health analytics dashboard populated with data from the electronic medical records of every patient admitted to the Hospital. The dashboard scans patient data in real-time, identifies patients exhibiting symptoms associated with heightened risk of kidney injury, and alerts the attending physician to intervene and take preventative measures. The Kidney Health Dashboard has had a transformative impact: In its first year of operation, the number of acute kidney infection cases declined by 34%.

As a practicing clinician and Dr. Vaidya's colleague, Dr. Clarke has seen for herself how providers across



Dr. Vaidya (left) and Dr. Clarke (right) at a data center at Phoenix Children's discussing how improvements in data processing can help more patients.

the Hospital are improving their practices using similar tools. Dr. Clarke remembers what it was like to sift through stacks of paper files to review a patient's case. Now, all that data is summarized, organized and centralized in user-friendly dashboards, and she feels more confident in her own practice as a result.

"We now have thousands of alerts checking everything from dosing, to allergies to patient susceptibility to other conditions," Dr. Clarke says.

"The end result is that we're making things better for

our patients, we're providing better care, and we are a better Hospital for it."

Dr. Vaidya agrees that the technological advances of the past decade have been incredible for Phoenix Children's. "Data gives our clinicians superpowers!" he says. "Almost every day we are seeing so many opportunities to use data to help our doctors make faster and safer decisions for patients. By surrounding our specialties with the right technology resources, we can make exponential progress."

LEADERSHIP CIRCLE: FUELING INNOVATION TOGETHER

Imagine the worst happens. A hospitalized child is in critical condition. Suddenly, their breathing halts; their heart stops. A "code event" has occurred and the clinical team must respond within minutes to prevent permanent organ damage, and even death.

At Phoenix Children's Hospital, hundreds of children experience abrupt clinical decline requiring urgent intervention every year. So a group of Phoenix Children's clinicians asked themselves: What if we could anticipate these codes before they occur? Could the electronic medical record make it possible to predict a code event by aggregating, monitoring and analyzing every child's symptoms in real time?

In 2017, the team pitched the idea to the Phoenix Children's Hospital Leadership Circle giving group and donors took action. The team was awarded \$188,000 to develop and implement the WATCHER system – a screening tool that utilizes discreet data from the electronic medical record to continuously measure a child's risk of clinical decline, alert the clinical team to urgently intervene and avoid a catastrophic change in the child's condition.

Leadership Circle is a committed group of community members who come together to support innovative initiatives that make a powerful difference for children and families. Over the past decade, Leadership Circle has fueled the culture of innovation for which Phoenix Children's has become known. For more information on how to get involved, visit www.phoenixchildrensfoundation.org/giving-groups/leadership-circle.

WHY THEY GIVE

JOAN AND LARRY JARNIGAN

Investing in the Future of Heart Care

Joan and Larry Jarnigan ran the family farm together. They grew cotton, vegetables, grain and melons. Their daughters sold fruit and sweet corn at the farmer's market every spring. And they did everything they could to keep up the family farming tradition as the landscape of rural Arizona changed around them.

But at 52, Larry was hit with a heart attack – his first of four over the next 20 years. Larry was devastated, but says that his faith, his family, and his commitment to service saw him through.

"It was hard to take," says Larry. "I had to give things up, including farming. But even so, I am very fortunate. I am so very blessed to be here."

In the wake of Larry's health scares, the Jarnigans devoted themselves to giving back. They volunteered to help people in hospice care. They provided free English classes to farmworkers. And they traveled to Africa as part of a mission to help children suffering under the strains of poverty.

Drawn to the cause of children's health, Joan also joined WINGS, the women's board at Phoenix Children's Hospital. There she learned that Phoenix Children's Heart Center is one of the only hospital programs in Arizona using 3D printing technology.

Curious about how a 3D printer could possibly be used in heart care, the couple took a tour of Phoenix Children's cutting-edge Cardiac 3D Lab. They met Dr. Stephen Pophal, who told them that cardiologists at Phoenix Children's were using 3D printers to create intricate models of patient hearts for more precise diagnoses. They learned that by harnessing the power of this technology, Phoenix Children's had become a national leader in innovative heart care.

When Dr. Pophal heard about Larry's condition, he had an idea – to show the Jarnigans the power of 3D technology by creating a model replicating every detail of Larry's heart and gaining some new insight into his condition in the process.

"I was so impressed," says Larry, "Seeing what they could do just blew me away."

Larry and Joan decided then and there to make a gift to the Cardiac 3D Lab. Dr. Pophal says that their support will allow Phoenix Children's to remain at the forefront of 3D organ printing and continue to bring innovative solutions to children in need.

"Having my own heart issues, I could relate," says Larry. "Here are these poor kids without a chance, and this technology gives them that chance. That's just unbelievable."

"Having my own heart issues, I could relate. Here are these poor kids without a chance, and this technology gives them that chance. That's just unbelievable."

The Jarnigans with a 3D model of Larry's heart that was created at Phoenix Children's.





WHY THEY GIVE

NEXTPHASE ENTERPRISES

A Family Business Built to Serve

Michelle West's twin daughters were born premature and spent the first six weeks of their lives in intensive care. The twins recovered and are now healthy teens, but Michelle recalls the agony of the experience as if it were yesterday. What sticks in her mind is the parents who were less fortunate, and the months or even years that some of them spent by their child's bedside, waiting for a breakthrough.

So when Mike Parker, the Founder and CEO of the company for which she works, NextPhase Enterprises, decided to make a gift to upgrade the monitoring technology in Phoenix Children's Intensive Care Unit, Michelle felt profound gratitude. Not only for the powerful impact that she knew the technology would have for doctors and parents fighting to keep children alive, but to work for a company where giving and service are fundamental to the culture.

"As individuals, many of us would not be able to give a gift like this, so it's really nice that we're able to contribute through our work and that our company would do something this big," says Michelle. "It's pretty incredible."

The implementation of the four new multimodal neurologic monitors in Phoenix Children's Intensive Care Unit will represent a massive upgrade to the Hospital's ability to care for children with acute brain injuries. The monitors will allow doctors to analyze vast quantities of data on patients more efficiently and make more informed decisions about treatment.

"This gift, and this technology, is going to vastly improve care at Phoenix Children's," says Dr. Brian Appavu, pediatric neurologist. "It's going to put Phoenix Children's on the map as one of the most advanced centers for the management of acute brain injury in the country. We couldn't be more grateful."

"This gift, and this technology, is going to vastly improve care at Phoenix Children's. It's going to put Phoenix Children's on the map."



NextPhase Enterprises was founded on a vision: combine the values of a family company with a dedicated spirit of service. Staff are not only encouraged to pursue causes they care about; they are also supported to volunteer – including at Phoenix Children's – on company time.



"We work hard and we like to give back. And having a doorway into giving through my company has been phenomenal."

Anthony Torres, Logistics Manager, collected nearly 15,000 diapers for low-income parents.



From left: Anthony Torres, Logistics Manager; Michelle West, Assistant Controller; Mike Parker, Founder and CEO; Dawn Taylor, Senior Account Manager; April Riegler, Public Relations Director.



“It changes your thought process. You realize you’re not just doing this job for the benefit of yourself, you’re doing it for others too.”

April Riegler, Director of Communications, started a non-profit in Rwanda to help hungry kids.



“It is an amazing feeling as an employee, to work together to impact lives and create real change.”

Dawn Taylor, Senior Account Manager and Phoenix Children’s volunteer.

SIGNATURE EVENTS

EVERYONE WHO PARTICIPATES MAKES AN IMPACT

Phoenix Children's Hospital Foundation events represent an opportunity to participate in fun, inspiring and unique experiences with our vast community of supporters. The proceeds of every event are used to give children and their families the best possible experiences and outcomes.

Beach Ball

On February 22nd, guests dove into the spirit of the French Riviera at the 27th annual Beach Ball. Guests enjoyed a festive evening that raised a record **\$2 million**. Presenting sponsors were the local companies of Berkshire Hathaway Energy - BHE U.S. Transmission, Long Realty and BHE Renewables. Additional sponsors included APS, Discount Tire, Anthony Rizzo Family Foundation, the Czerwinski Family and Kasey Thompson.



MARK YOUR CALENDAR NOW! YOU CAN MAKE AN

TBD
Power Play
PowerPlayPCH.com

APRIL 14, 2020*
ABC15 Telethon
PCHHeroes.com

TBD
Telemundo Telethon
UnidosPorPCH.com

*All dates and events are subject to change. Visit givetopch.org for the latest information.



Phoenix Children's Hospital Golf Tournament

On November 22nd, the Phoenix Children's Hospital 21st Annual Golf Tournament brought together 288 golfers to enjoy a day on the course and fundraise for the patients at Phoenix Children's. The **\$600,000** raised will help the Hospital launch critical new programs, purchase essential equipment, conduct cutting-edge clinical trials and much more. Since its inception, the golf tournament has raised \$7.3 million. Presenting sponsors were CBRE and MJ.



Ignite Hope

In one event spanning two locations, more than 3,000 people gathered in a heartfelt show of support for Phoenix Children's patients during the Ignite Hope holiday candlelight walk. Walkers held battery-lit candles and participated in festive holiday fun, including face painting, photos with Santa and the ceremonial lighting of holiday trees. The event raised **\$470,000** for the Hospital.



Concours in the Hills

Against the lush backdrop of the sprawling Fountain Park, car enthusiasts from across the Southwest showcased a record 1,052 collector and exotic vehicles at the 7th annual Gila River Hotels & Casinos Concours in the Hills, a Scuderia Southwest Event. The **\$250,000** raised will help Phoenix Children's provide world-class care to its patients.



Dine with Your Dog

The 13th annual Phoenix Children's Hospital Dine With Your Dog event was held on February 8th at Monterra at West World. Dog lovers were treated to brunch while their pooches were pampered, posed for photos and enjoyed a morning out. The event raised **\$131,000** to support the Animal-Assisted Therapy program, which helps motivate, soothe and lift the spirits of patients, many of whom are fighting for their lives.

IMPACT AT THESE UPCOMING EVENTS

NEW!

JULY 24 AND 25, 2020*

eSports

eSportsPCH.com

AUGUST 2020*

KTAR and Arizona Sports Give-A-Thon

GiveAThonforPCH.com

OCTOBER 3, 2020*

Phoenix Children's Hospital 5K

PCH5K.com





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GIVE TODAY

Help Phoenix Children's drive
discovery and innovation by donating
today at [GiveToPCH.org](https://www.GiveToPCH.org)

Remember to check out the ABC15 Telethon on April 14th.
For more information, visit [PCHHeroes.com](https://www.PCHHeroes.com)

Phoenix Children's Hospital Foundation

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