

INNOVATE



Children's
Hospital of Pittsburgh

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COMMUNITY REPORT 2019



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INNOVATION ABOUNDS AT UPMC CHILDREN'S HOSPITAL OF PITTSBURGH

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Innovation abounds at UPMC Children's Hospital of Pittsburgh, and so much of the groundbreaking work our physicians, researchers, and specialists do is made possible thanks to supporters like you. Your gifts to Children's Hospital of Pittsburgh Foundation help to make our hospital among the very best, earning us the eighth position on this year's *U.S. News & World Report* Honor Roll of America's Best Children's Hospitals. Donations fund the programs and services that are not covered by insurance, yet, are integrally important in caring for the whole family — mind, body, and spirit.



In this Community Report, you'll read stories about pioneering initiatives, cutting-edge discoveries, and leading therapies. You'll meet researchers like Dr. Liz Miller, whose community-based work measures the effectiveness of interventions to prevent teen violence before it ever occurs. You'll read about Patrick, a 12-year-old who found healing through Creative and Expressive Arts Therapy. And you'll meet the McCachrens, a Supportive Care family who maintains hope despite unimaginable loss.

These stories and innumerable others illustrate the importance of integrated care that addresses children's physical health, as well as their social, emotional, and spiritual well-being.

So please enjoy this glance back at the many achievements we attained this past year with your generosity. Then join us as we dream up what's next.

Thank you, from the bottom of my heart, for giving us the support we need to continue to innovate.

A handwritten signature in blue ink that reads "Rachel A. Petrucelli".

Rachel A. Petrucelli
President, Children's Hospital of Pittsburgh Foundation



Q&A with UPMC Children's President Mark Sevco

In June 2019, Mark Sevco was appointed president of UPMC Children's Hospital of Pittsburgh. Mr. Sevco has served UPMC in various capacities for nearly three decades. Prior to his appointment with UPMC Children's Hospital, he was the Chief Operating Officer of UPMC Pinnacle, a multi-hospital system in central Pennsylvania. Here, he explains his vision for UPMC Children's and his thoughts on the role of philanthropy.

Q. Tell us a bit about yourself.

A. I've been with UPMC for 27 years and worked for eight different hospitals within the system, including UPMC Children's. I was here 15 years ago, and it's wonderful to be back!

I'm originally from central Pennsylvania. I have my bachelor's degree in applied mathematics and my master's in business administration and in health administration from the University of Pittsburgh. I'm a big Pitt fan and love sports.

I'm married to my lovely wife, Christine. We have three children: Nikki, 22, Julia, 20, and Jack, 17.

Q. How did you get started in the health care field?

A. I've always been interested in the service industry. When I was in my dual master's degree program at Pitt, I completed an administrative residency program at UPMC Presbyterian that really solidified my interest in the field. The hospital had just merged with Montefiore, so it was a period of expansion. I saw physicians and staff who worked so hard caring for patients with complex issues, and it inspired me.

As an administrative resident, I learned about measuring patient satisfaction, contributing to strategic planning efforts, and aligning resources to support clinical teams to enhance the patient experience. It was fascinating, rewarding work.

Q. What is your vision for UPMC Children's?

A. I want us to have the collective ambition to be the best children's hospital in the country. I don't mean the biggest, necessarily, but the best, as measured in terms of our overall impact, service to the community, employee engagement, and patient experience. We want to be an industry leader in technology and discovery. We have amazing physicians, scientists, and staff who work every day at UPMC Children's to make an extraordinary difference; part of my job is to make sure they have the right resources to be successful and keep them inspired and passionate about the remarkable work they do.

Q. What challenges do you face as president?

A. Providing world-class pediatric care is very resource intensive. Balancing the needs between clinical service, teaching programs,

and academic research is challenging. With our ambition to be the best, we have many investments to make while balancing a budget. My team works hard every day to make decisions to support the best ideas. We stay focused on a singular goal to provide the ultimate patient experience and have plenty of work to do. As the only pediatric hospital in the region, families depend on UPMC Children's to provide expert subspecialty care. While we work very hard to meet this need, we've found that too often families must wait a long time to get an appointment with some of our specialists. We are changing that.

One of my priorities as president is to develop a digital front door for the hospital, a family-focused mobile platform that gives parents the chance to easily schedule appointments, better access a child's medical information, and even speak to a UPMC Children's doctor any time — right from their smartphone. We plan to implement many changes, but to do so we'll need to improve our systems, further invest in our great telemedicine program, and recruit additional world-class pediatric subspecialists. We desire to be a world leader in health care innovation. Of course, all these things take time and significant resources, but this is one of the many areas where philanthropy can make a big difference.

Q. Tell us about your management style.

A. I believe strongly in servant leadership and surrounding myself with a team that is diverse and smarter than me. I enjoy working on teams that strive to be the best

in class. I am proud to say that we have an amazing leadership team at UPMC Children's. And while I am results-focused, I want decisions to be participative and inclusive, with input from the team. I do my best to be a very visible leader and one who listens. I also want UPMC Children's to be an employer of choice, where every single staff member is treated with dignity and respect.

When I started at UPMC Children's, I spent my first 90 days on a listening tour, observing, gathering information, and collecting feedback from front-line staff. But for us to be the best we have to proactively change, and I continue to deliver that message and make changes too. I enjoy empowering staff to achieve their best and try to not get in the way of great ideas and movement. I am a firm believer in "what is recognized is repeated." Sometimes it just takes encouragement and a thank you for great things to happen.

Q. What would you like patient families to know about you?

A. I want families to know that I care. My promise is to work hard every day with an amazing team so parents can rely on us whenever they need us. Serving children and families is the most important part of our work. I view it as a privilege to work at UPMC Children's. I want to build upon our hospital's exceptional reputation for advanced technology to deliver what parents want in a compassionate way. I am passionate about the patient experience and want parents to know that UPMC Children's strives to provide the ultimate patient experience, and we measure our success one child at time.

Q. How do charitable gifts contribute to your goals for the hospital?

A. Let me begin by saying that we are incredibly grateful for Children's Hospital of Pittsburgh Foundation and our donors. Donations contribute to things like our wonderful Child Life Department and Creative and Expressive Arts Therapy. These programs welcome, comfort, and distract children who are here in the hospital — giving them the chance to build good memories during what can otherwise be a very difficult time.

Charitable gifts allow us the remarkable opportunity to accelerate our vision and goals and help us achieve extraordinary results for patients and families — setting us apart from other institutions and creating a platform to be the best children's hospital in the country.

The McCahren Family: Zoe, Zayva, Tim, Cassie, and Zach, who holds a photograph of his late brother, Zane



NO MATTER THE PATH

How UPMC Children's Supportive Care team is changing the way children and families experience death

"I can remember the first time I met Carol May," Cassie McCahren recalls. "I was sitting outside of the Pediatric Intensive Care Unit (PICU) sobbing uncontrollably. Carol knelt down beside me and simply said, 'What can I do?'"

Cassie and Tim McCahren never expected that UPMC Children's Hospital of Pittsburgh would become something of a second home for them. In 2012, with two healthy children, Zachary, now 14, and Zoe, now 12, the couple gave birth to their third child, a little boy named Zane.

Immediately after he was born, Zane was life-flighted from a hospital near the family's home in Johnstown to UPMC Children's Hospital. Children's physicians discovered that Zane had multiple congenital anomalies.

With their tiny baby hooked up to all sorts of machines, Cassie and Tim learned that Zane was gravely ill. Physicians explained that he would likely never talk or walk or breathe on his own.

Zane spent his first 88 days of life in the hospital. At 3 months old, with a feeding tube, trach, and other assistive devices, he was discharged home; he would need around-the-clock care. Zane's condition also meant frequent hospitalizations at UPMC Children's.

It was during one of those hospitalizations when Zane was 2, that the family met Carol May, RN, MSN, MBA, CHPPN, manager of Children's Supportive Care Program. Zane's physicians in the PICU were worried he might not make it home. They called in the Supportive Care team for consultation with the family. "Right from the beginning, Carol was an amazing support," Cassie says. "I don't know what we'd do without Supportive Care."

For the next year, Zane struggled with one illness after another. Through it all, Carol and her team provided the McCahrens with support.

And then, in fall 2015, Zane's condition worsened. On November 29, 2015, surrounded by those who loved him most, Zane died at home in his mother's arms. He was 3 years old.

While there is nothing in this world to prepare a family to bury their child, the Supportive Care team at UPMC Children's made an unfathomably difficult situation a little bit easier to bear. "We knew what to expect thanks to the Supportive Care team," Cassie shares. "They were with us then, and they've been with us ever since."



A Comprehensive Program

Founded in 2003 by the hospital's chief medical officer, the late Dr. Eugene Wiener, the Supportive Care Program at UPMC Children's has grown exponentially in recent years. "When we started over 15 years ago, there were just two of us on staff," Carol recalls. "Now, there are nine." Led by Carol and medical director Scott Maurer, MD, the team also includes a second physician position, a physician-researcher, three advanced practice providers, a bereavement coordinator, and a sibling bereavement camp coordinator.

The team works across hospital departments to provide individualized care and support to children facing life-limiting illness and their families. With an emphasis on coordinating medical treatment so that each child's

quality of life is optimal during all stages of his or her illness, the team gets involved early, even when a child's prognosis is uncertain. "We want to improve quality of life for every patient we treat," Dr. Maurer states. "If this leads to wellness, wonderful; but if not, we'll still be there."

One of the first pediatric palliative care programs in the region, Children's Supportive Care department has been a leader in the care of children with life-limiting conditions. To educate providers, the team hosts the Annual Palliative Care Conference and offers ongoing training opportunities for physicians, specialists, and students. They further contribute to the field through participation in national research initiatives, like the PRISM clinical trial, exploring resilience in adolescent and young adult

cancer patients, and the Pediatric PRO-CTCAE™ study, which gives children and adolescents a tool they can use to describe their symptoms during oncology treatment.

But, perhaps most importantly, Children's Supportive Care team works day and night to meet the physical, emotional, social, and spiritual needs of the children and families entrusted to their care. In 2017, with philanthropic support from community partners like the A. J. and Sigismunda Palumbo Charitable Trust, the team launched Camp Wakchazi, a summer residential camp for bereaved siblings. They also host monthly support groups, provide virtual visits to keep families at home, offer ongoing outreach to bereaved parents, and work with families to prepare legacy projects like family tree paintings, handprint models, and heartbeat

Above: Children's Supportive Care leadership team: Scott Maurer, MD, and Carol May, RN, MSN, MBA, CHPPN

recordings. These family-centered initiatives — covered entirely through charitable contributions — are priceless, giving moms and dads the chance to hold a little one's hand or listen to a child's heartbeat, long after his or her passing.

The Journey Continues for the McCachrens

In 2018, while still grieving the loss of their child Zane — who never received a confirmed diagnosis — Cassie and Tim learned they were expecting. On April 28, two years after Zane's death, the family welcomed their fourth child, a baby girl named Zayva.

But sadly, baby Zayva was born with many of the same congenital anomalies as her brother before her. And she, too, is expected to lose the battle with her disease.

"Sometimes we grieve for the things our daughter will never get to experience," Cassie shares. "But with the Supportive Care team's help, we find many more moments of hope and joy."

Like the joy of big brother and sister, Zachary and Zoe, returning home from Camp Wakchazi, with sun-kissed skin and stories of the friends they've made. Or when Zayva pitches a full toddler-sized fit about her mom coming at her with a suction tube. Or when everything's quiet, and the family can reflect on the path Zane forged for the little sister he never knew.

As Dr. Maurer summarizes with Carol nodding in agreement, "Regardless of where the path leads for Zayva or any of the kids we serve, we will walk this journey together."



Above: Zayva at 18 months, battles the same debilitating genetic disorder as her brother Zane

BECAUSE YOU GIVE

When a child's inner light burns so brightly during their lifetime, it is often impossible to dampen, even when they pass on from this world. This is exactly what happened when donors Cyndi and Jim McGinnis said goodbye to their beautiful daughter Maggie Elder in 2012. Diagnosed with Ewing's sarcoma at age 11, Maggie radiated optimism, faith, and incredible strength, touching the hearts of all she encountered. To honor Maggie's life and memory, Cyndi and Jim established the Miracles from Maggie Endowed Fund for the hospital's Supportive Care Program, so that other kids could receive the same compassionate support that Maggie did.

The importance of offering personal Supportive Care and the presence of Children's phenomenal Supportive Care team have also inspired many others to give. Most recently, longtime Children's advocates Catharine and John Ryan III established the Catharine M. and John T. Ryan III Supportive Care Endowment. With their generous gift, the Ryans will help to sustain the around-the-clock care provision that makes Children's Supportive Care Program so exceptional.

We remain infinitely grateful for the funding provided by the McGinnis and Ryan families. Thanks to their compassion, children and families facing the most difficult of circumstances will receive the support they need now and for years to come.



When her child was sick in the hospital, Jenny Monahan prayed. Her 11-year-old son Patrick was experiencing seizures at the time. Physicians at UPMC Children's Hospital of Pittsburgh diagnosed him with a benign brain tumor. He would need brain surgery and extensive follow-up treatment.

During one of their stays at UPMC Children's in December 2018, Patrick underwent a five-hour surgery to remove the tumor. After two days, with her little boy still recovering in his hospital bed, Jenny snuck away to the hospital's chapel. There, kneeling amidst the soft glow of the quiet chapel, she asked God to heal her son.

As she exited the space to head back to Patrick's room, she saw something incredible. In the sunlit Atrium adjoining the chapel, she found Patrick. Not only was he up out of bed — he was actively playing with Jenny's parents!

"It felt like a miracle," Jenny remembers, her voice breaking a bit. "Patrick had been through so much, but there he was, having fun. Children's is an amazing place."

Patrick checks out Children's CEAT space with program coordinator Kory Antonacci, MSEd, LPC, MT-BC

BEHIND THE CURTAIN



The Role of Creative and Expressive Arts Therapy

Jenny and her husband, Kevin, credit Patrick's recovery to not only their faith, but also the talented physicians, nurses, and therapists who cared for their family along every step of the way. Chief among them, Kory Antonacci, program coordinator for the hospital's Creative and Expressive Arts Therapy (CEAT) program and board-certified music therapist.

"Patrick's condition necessitated multiple hospitalizations, including a week-long observation stay with an EEG. He was restricted to his hospital room with electrodes stuck to his head," Jenny explains. "This could have been a miserable experience, but it wasn't thanks to CEAT."

Kory would sit with Patrick in his hospital room, and they would play music together. Jenny says, "It made all the difference for Patrick and for all of us. I believe the music therapy was a key part of his recovery."

A Masterpiece of Hope

In 2016, Children's Hospital of Pittsburgh Foundation launched the *Masterpiece of Hope Campaign* in support of CEAT. To date, generous community members have contributed nearly \$8 million to completely transform 3,000 square feet of space on Children's sixth floor.

Through the Dream Big Studio, Matt's Maker Space, and the Nora Grace Kaufman Center for Creative Arts Therapy, Children's now offers an ultramodern, dedicated space where patients and families can find healing through the creative and expressive arts.

Through the Eyes of a Child

On a sunny day in October 2019, ahead of a routine follow-up visit for a now 12-year-old Patrick, we tagged along as Kory led the seventh grader through the new CEAT space. With a grin from ear to ear, Patrick listened attentively as Kory showed him around.

In the hospital's Atrium — the very spot where Jenny found Patrick playing just 48 hours after brain surgery late last year — stands the new Dream Big Studio. Led by Riley Hammond and Dave Rubin, the state-of-the-art TV and radio broadcasting studio offers kids the opportunity to lead live and pre-recorded broadcasts, while giving patients who are bedridden the chance to experience hospital events in real time.

Around the corner is the new Matt's Maker Space, providing STEAM activities so that kids and parents can tinker, play, and learn together. Through double doors down the hall is the Nora Grace Kaufman Center, where an interactive nook lets kids imagine themselves in an open field, with flowers lining the earth and bubbles and stars floating overhead.

To the right, a large music therapy studio houses a grand piano, recording equipment, and room for patients to drum, jam, or sing. Music therapists Nicole Steele and Brittany Stone use music to connect with patients and address physiological responses, verbal processing, and social and emotional needs.

Across from the music studio, a private art therapy room glows invitingly. Specially designed for focused one-on-one sessions, the space makes art therapy accessible to all children, including those

with developmental barriers. Art therapists Kate Gibson and Katie O'Connor help kids find physical and emotional healing through creative expression.

Past the studios, the Creation Station provides a wide-open space with a pottery nook, virtual reality (VR) painting technology, a digital design center, and tons of space for group work. Through the doorway with marquis lights overhead, you'll find the theater space, complete with ballet barres, mirrors, and a stage where kids can perform.

It's here we pause so that Patrick can take it all in. That is, until Kory suggests a duet, and she and Patrick break into song.

Patrick Plays On

As Jenny and Kevin watch their son follow Kory's lead in a rendition of *Hello, Dolly*, they can't help but to smile.

Although Patrick continues to require care at UPMC Children's, he is doing well, excelling in the gifted program at Seneca Valley and staying active in martial arts and school musicals. And thanks to CEAT, the 12-year-old actually looks forward to his trips to the hospital.

"When your child is sick, all you do is worry. The fact that Children's uses CEAT to bring joy to kids and their families gives people relief and hope during an incredibly stressful time," Jenny says. "This place is wonderful. We can never fully express our gratitude to Children's and its team."

Previous Page Top: Music therapy patient Jimmy leads a dance party in the new space

Previous Page Bottom: Art therapy patient KK experiences the VR painting system

Masterpiece of Hope Campaign

\$10,000+ Donors

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FINDING

UPMC CHILDREN'S DIABETES WRAPAROUND PROGRAM HELPS TEENS BETTER MANAGE THEIR HEALTH

BALLGAME

It's hard enough being a teenager. With schedules filled with school, homework, and activities, today's teens have a lot on their plates. Throw in a chronic, complex disease like type 1 diabetes (T1D) and some kids reach a critical tipping point — their health left hanging in the balance.

Emmy Green is one such teenager who is juggling an awful lot. At 14, Emmy works hard at school, takes dance class each afternoon, and cheerleads three to four times a week. Family life and friends only add to the equation, leaving Emmy with little time for the rigor required to adequately manage her T1D.

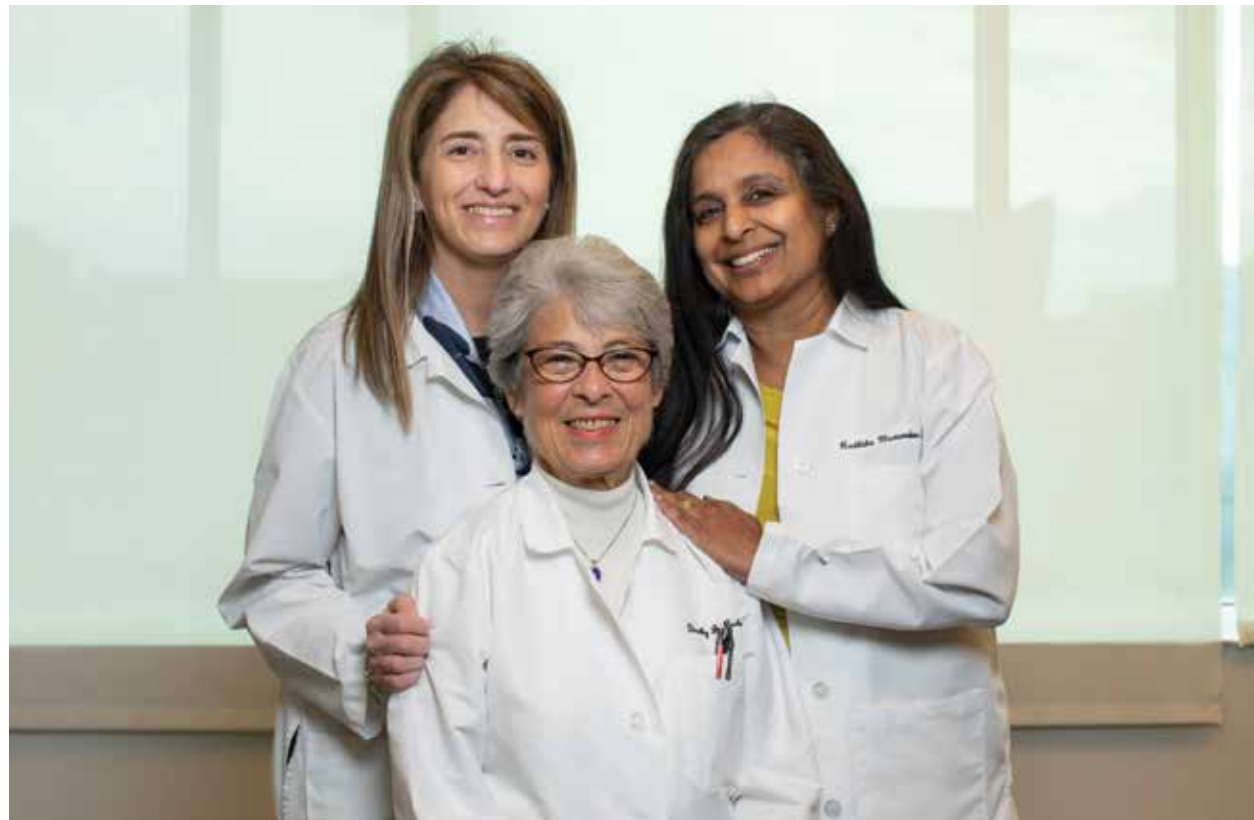
"It's a problem," Emmy's mom, Tracey, shares. "I worry about her all the time."

Emmy was first diagnosed with T1D when she was 8 years old. The family was on a ski trip when Emmy kept stopping to drink water. Concerned, Tracey took Emmy to the pediatrician the next day.

Emmy's labs revealed that her blood sugar was dangerously high. Her parents rushed her to UPMC Children's where she was immediately admitted.

It's here that Emmy was given the life-altering diagnosis of T1D. With no known family history of the disease, Tracey and her husband, Bill, were taken aback. They would need all the help they could get to handle Emmy's diabetes.

Emmy, 14, during a recent trip to Children's



A World Leader in Diabetes Care

Thankfully, Emmy was in good hands. Endocrinologists at UPMC Children's have played a major role in the care of children with diabetes for more than three decades. Led by Chief Radhika Muzumdar, MD, UPMC Children's Division of Pediatric Endocrinology and Diabetes is one of the largest pediatric diabetes treatment centers in the world, serving about 2,500 patients each year. Consistently ranked as a top program by *U.S. News & World Report*, the division provides each child with individualized, comprehensive treatment.

In addition to meticulous patient care, the division emphasizes a commitment to cutting-edge research. UPMC Children's basic

science research physicians are expanding our understanding of the cellular processes involved in diabetes while exploring innovative therapies for treatment.

With world-renowned physician-researchers like Dorothy Becker, MD, whose 30 plus year career has unveiled landmark findings in the prevention and treatment of diabetes, the division additionally prioritizes important clinical research. "Our work contributes to the field with multicenter studies examining the safety and effectiveness of current treatments, as well as the promise of new interventions to obtain control and thwart complications," Dr. Becker states. "Equally important are our trials aimed at the delay or prevention of diabetes. In fact, recent results

suggest that, with more effort, we can possibly make prevention a reality." Through clinical trials and other groundbreaking studies, Children's remains at the forefront of important diabetes research.

Addressing an Important Need

Adolescence brings with it a particular set of challenges for kids living with chronic diseases like diabetes. From the physiological changes associated with puberty, to social pressure and exposure to things like vaping and alcohol, many teens struggle to keep up with the regimen necessary to maintain good health. In fact, a 2015 American Diabetes Association study found that less than 25% of youth with T1D adequately controlled their blood sugar

levels. "This is very concerning," Dr. Muzumdar explains. "Young people with poor glucose control are at significantly greater risk of serious, life-limiting complications later in life."

To address the specific challenges facing teen patients like Emmy, Children's Division of Pediatric Endocrinology and Diabetes launched the Diabetes Wraparound Program (DWP) in 2019. DWP "wraps" teenage patients living with diabetes with the care and guidance they need.

Under the leadership of Ingrid Libman, MD, PhD, director of the hospital's diabetes program, and in partnership with the Behavioral Health Division at UPMC, DWP gives young people and their families the tools they need to improve T1D management. The initiative draws on the successes learned through similar programs in the mental health field to empower young people and their families to take ownership of their diabetes care. Funded through charitable contributions, DWP provides both community-based and clinical coaching. "Treatment is inclusive of physicians, facilitators, and peer partners," Dr. Libman explains. "And communication is based on a patient and family's preferences, whether face-to-face, phone, or email/texts."

Through personalized plans with identified support systems for each patient, UPMC Children's specialists strive to give teens enrolled in the program the knowledge and confidence they need to build support, improve long-term T1D management, and prevent complications.

Finding the Right Balance for Emmy

When Emmy was first diagnosed with diabetes, Tracey and Bill were unprepared for the many life changes the disease necessitated for Emmy and their family. "I can remember staring at food labels in the supermarket with tears in my eyes," Tracey recalls. "Between counting carbs, monitoring glucose levels, and staying on top of insulin injections, we were completely overwhelmed." Yet, they eventually got the hang of it, and for many years thereafter, Emmy did quite well.

Then about a year and a half ago, she started having a hard time. Emmy would tire more easily; at times, she'd feel sick after a long cheer or dance practice. "She doesn't like to test her blood sugar in front of other kids, and she'll miss her injections," Tracey explains. "I'll remind her, but then it seems like I'm nagging. It's been a challenge."

So when UPMC Children's endocrinologists first approached Tracey about enrolling Emmy in DWP earlier this year, she jumped at the opportunity. Tracey has high hopes for the program. She wants to learn how to support Emmy without being overbearing. She also wants Emmy to better understand what can happen if she doesn't take care of herself.

While enrolling in the program wasn't exactly Emmy's choice ("Mom kind of made me," Emmy says), she, too, expects good things from DWP. "I want to learn to be more confident in managing my diabetes — for the long run," she states.

And on that point, mom and daughter agree.

BECAUSE YOU GIVE



Foundation Board Chair Cliff Rowe and his wife Diane know firsthand just how big a toll type 1 diabetes (T1D) can take on kids and families, as their grandson Anderson was diagnosed with T1D in 2016. In honor of the care Anderson (pictured above, left, with his cousin Kip) received at UPMC Children's, the Rowes gave the lead gift to support the Diabetes Wraparound Program. Thanks to their philanthropy, the future is looking brighter every day for families and kids living with T1D. This gift is just one of the numerous ways that Cliff, Diane, and the Rowe family make UPMC Children's a place of hope and healing, and we could not be more grateful for their generosity.



Above: Ingrid Libman, MD, PhD, Radhika Muzumdar, MD, and Dorothy Becker, MD, lead Children's renowned diabetes program

THE PATIENTS BEFORE US

UPMC Children's New MIBG Therapy Suite Promises to Change the Course of Care for Kids Diagnosed with an Aggressive Cancer

When Casey Carol Neff was just a baby in her mother's arms, her grandmother spotted something. There was a lump on 11-month-old Casey's neck. "No one else even noticed it," Casey's mother, Cindy, recalls. "And, honestly, I didn't think too much of it."

But, just to be safe, Cindy took Casey to the pediatrician, who referred the family to UPMC Children's Hospital. Following a series of tests, physicians delivered the awful news: the lump was a tumor. Casey had high-risk neuroblastoma (NB), a cancer that forms in certain types of nerve tissue and almost always affects children under the age of 5. Casey's chance of survival was about 40%.

"I couldn't believe it," Cindy says. "I remember driving back to the house to pick up Casey's sister, Erin, who was 5 then. I went into Casey's bedroom and just sat down and cried. I kept thinking that she might never come back home."

Those next 18 months were a complete blur for Cindy and her family. Baby Casey was admitted to

UPMC Children's. She had several rounds of chemotherapy treatment, surgery to remove the tumor, a lengthy stem cell transplant, and radiation to kill any remaining tumor cells.

After a year and a half in and out of the hospital, seemingly endless procedures, and constant monitoring, Casey started to get better. Her tumor was all but gone, with only some calcified residue remaining. The standard treatment was complete.

It was then that the family was faced with a dilemma: Casey's oncologist, Jean M. Tersak, MD, asked whether they wished to enroll Casey in a clinical trial to test the effectiveness of an experimental new antibody therapy to try to reduce Casey's risk of recurrence and increase her chance of survival. The trial would mean another five months of treatment for a then 2½-year-old Casey.

After careful consideration, and with the knowledge that Casey's neuroblastoma was otherwise likely to return, the family agreed.

Story continued on page 31



Above: Casey with her oncologist Jean M. Tersak, MD, during treatment as a toddler

Left: Casey and Dr. Tersak today



The Importance of Clinical Trials

UPMC Children's is a member of the Children's Oncology Group (COG), the world's largest group devoted to childhood cancer research. Through this collaboration with the COG, Children's is among an elite group of hospitals participating in the latest cancer clinical studies available to pediatric patients. UPMC Children's is one of only 21 COG institutions in the country with permission to conduct research in early drug development, bringing hope to children whose disease has come back or not responded to treatment. Currently, our hospital offers more than 100 active clinical oncology trials.

As director of UPMC Children's Clinical Oncology Research Program, Dr. Tersak oversees a team of research associates, nurses,

and regulatory specialists — much of the team's work is supported by charitable contributions. "Here at Children's, philanthropy helps to fund the infrastructure we need to run these studies," she states. "With donor support, we're uncovering data that will help us treat the patients before us today and getting closer to developing the cures that will allow us to save the patients of tomorrow."

UPMC Children's New MIBG Therapy Suite

For the past few years, physician-researchers like Dr. Tersak have heralded the benefits of MIBG (meta-iodobenzylguanidine) therapy in the treatment of high-risk or relapsed NB — the type of cancer that affected Casey Neff. But it wasn't until the hospital received a very generous gift from

Stephanie McMahon Levesque and Paul "Triple H" Levesque that Children's MIBG Therapy Suite became a reality.

Originally developed as a blood pressure medicine, MIBG is coupled with a radioactive iodine called I-131 for NB treatment. The therapy is delivered directly to the tumor cells via IV, and treatment is relatively painless. However, because of the radiation, a patient must be quarantined in a special lead-lined room for 3-4 days.

"While MIBG therapy is not a cure for relapsed high-risk neuroblastoma, it has been shown to elicit a response in some patients," shares Louis Rapkin, MD, the hospital's clinical director of oncology. "Children treated with MIBG therapy will almost always experience reduced pain

and better quality of life after treatment. We're now looking to understand whether MIBG will prove helpful in treating newly diagnosed patients."

In 2018, the McMahon-Levesque family committed \$1 million toward the construction of UPMC Children's new MIBG Therapy Suite — the only one of its kind in the region. Thanks to their exceptional support, the completed suite includes highly sophisticated equipment and an adjacent room where a parent can stay to provide support without radiation exposure. "The parent room is essential," Dr. Rapkin explains. "The family is always an integral part of treatment, but this is particularly true with MIBG because a child is quarantined."

The new MIBG Therapy Suite will initially treat children with hard-to-treat or relapsed NB. The hospital will then join a limited number of COG hospitals in a multi-institutional clinical trial that strives to further our understanding of the effectiveness of MIBG in combination with standard treatment when patients are first diagnosed.

Grateful for the Care She Received

It's been 12 years now since Casey Neff completed her antibody clinical trial. Today, the Mars Area High School sophomore appears to be the picture of health, active in her school and church.

The neuroblastoma trial the Neffs opted to enroll Casey in back in 2006 took a total of five months — with monthly, week-long hospitalizations for Casey to be infused with the antibody therapy.

Yet, if you ask Cindy, she'd do it all over again. "It was tough because we thought we were done, and then Dr. Tersak asked us about the trial," she recalls. "But the effect of the treatment was immediate. After the trial, Casey looked so much better. She was eating and playing again. It was like she was a different kid!"

For Dr. Tersak, that's testament enough to the importance of clinical research. "Ten years from now, I think MIBG therapy will be a frontline defense for kids with neuroblastoma," she says. "That antibody treatment that Casey had in 2006? It's now standard of care. I can't overstate the importance of these trials."

As for Casey? She's just grateful for the care she received, even if she can't quite remember much of it. In the future, Casey hopes to pursue a career in public relations or communications. But in the interim, she's happy to do what she can to give back, participating in ongoing studies and fundraising through events like Children's Hospital of Pittsburgh Foundation's annual *Walk for Children's*.

"I believe she was saved for a reason," her mom explains. "I can never say thank you enough to those who contribute to the care of kids like Casey."



BECAUSE YOU GIVE



Stephanie McMahon Levesque and Paul "Triple H" Levesque have supported UPMC Children's for many years, establishing Connor's Cure — a fund honoring 8-year-old WWE fan and cancer patient, Connor Michalek — in 2014. This past year, the Levesque Family took their support one massive step further by donating \$1 million to establish an MIBG Therapy Suite in the UPMC Children's oncology unit. Deeply passionate about ending all childhood cancers, the Levesque Family gives so that brave young patients can have the best possible chance of winning their fight against pediatric cancer. When asked what her personal message was for all the kids who would be receiving MIBG therapy in this state-of-the-art space, Stephanie responded, "Never give up. Keep fighting. Be strong. We're all in this with you." Triple H echoed her words, adding, "Hopefully that's the message we can spread, and when everyone gets involved, it can make a huge difference."

FUELING INNOVATION IN PATIENT CARE

Charitable gifts ignite cutting-edge thinking here at UPMC Children's. With your support, our talented physicians, nurses, and staff can dream big and think outside the box to provide our patients with trailblazing programs and services.

Thank you for partnering with us to push the boundaries of leading pediatric health care — healing hearts, minds, and bodies in the process.

Whole Child Wellness Clinic • With charitable support from Vanessa and David Morehouse, the Pittsburgh Penguins Foundation, PNC Foundation, HM3 Partners Independence Fund, Edith L. Trees Charitable Trust, Cathy and Sy Holzer, Dorothy and Neal Pollon and family, Christine and Mark Sevco, and other generous donors, UPMC Children's is piloting the Whole Child Wellness Clinic (WCWC). WCWC is a "medical home" that fills a gap in services for kids ages 3-12 struggling with chronic behavioral health issues. A unique collaboration between Children's and UPMC Western Psychiatric Hospital, WCWC offers behavioral and physical health care all in one, patient- and family-centered clinic. WCWC coordinates care to reduce the stigma, hassle, and confusion of siloed behavioral health services to help kids and families find the expert care they need.

Tele-cardiology for Newborns • When a baby is born with critical congenital heart disease (CCHD), early intervention can save their life. Working in concert with nurseries in 14 regional and rural hospitals, the Heart Institute at UPMC Children's uses telemedicine to interpret echocardiography for newborns. The tele-cardiology service allows physicians to fast track patients who are suspected of having CCHD, providing near-instant transmission of echocardiography to our hospital for interpretation results within three hours. Thanks in part to charitable gifts to the Heart Institute, participating hospitals can connect directly to our Children's imaging system. Last year, approximately 1,250 echocardiograms were transmitted to the Heart Institute for interpretation. Thank you to the donors who help us heal so many little hearts.

YourMomCares Brain Manager App • YourMomCares (#ymc) is a group of celebrity and influencer moms banding together to raise awareness and funds for children's mental wellness. This year, YourMomCares gave a generous gift to Children's Hospital of Pittsburgh Foundation to advance this vital mission in western Pennsylvania and beyond. Brain Manager is an easy, fun, evidence-based mobile app using live mental wellness coaches for early intervention with issues like anxiety and depression. YourMomCares enabled tests of the app with young people ages 16-22 from UPMC Children's Community Pediatrics practices throughout the region. Our hope is that this project empowers youth to engage in behavioral wellness practice so they can lead fuller, healthier lives. Because, as the saying goes, mom knows best!

iMRI • UPMC Children's is one of the only pediatric facilities to offer an Intraoperative Magnetic Resonance Imaging Suite (iMRI). Thanks to gifts from Carolyn and Mark Snyder, McKamish Family Foundation, and a generous legacy contribution from the Rose T. Weiss Trust, our iMRI Suite allows patients to be imaged during surgery. This cutting-edge technology gives surgeons the chance to better navigate tumor resections and other procedures without starting and stopping surgery or moving patients to another room for scans. UPMC Children's neurosurgeons consider the iMRI a gamechanger, improving accuracy and reducing risk in complex brain surgeries. Our thanks to these compassionate donors for investing in technology that improves critical care for our kids.

SMART Choices • UPMC Children's and UPMC Western Psychiatric Hospital run SMART Choices, a first-of-its-kind drug addiction prevention program, in all 45 UPMC Children's Community Pediatrics locations. With seed funding from CVS Health Foundation, SMART (Screening, Motivational Interviewing, and Referral to Treatment) Choices helps primary care providers identify those at risk, provide evidence-based interventions, and coordinate care for kids ages 11-18. Thanks to generous gifts from the Robert S. and Louise S. Kahn Foundation and Carolyn and Mark Snyder, the SMART Choices team will additionally pilot in Armstrong County an intervention model for kids who screen positive for risk of substance use. This next step will utilize a collaborative care model to develop goals that support kids and their parents with the aim to prevent substance use and addiction. Now, that's smart.

Dialectical Behavior Therapy (DBT) Course • Suicide is estimated to be the second leading cause of death among college students, yet skills-training programs to prevent student suicide are not available. Thanks to a very generous gift from Rob and Cindy Citrone and Citrone 33, the Dialectical Behavior Therapy (DBT) Project is measuring the effectiveness of a large-scale trial designed to reduce mental health problems and promote resilience in college students. Led by assistant professor of Pediatrics Carla Chugani, PhD, the initiative is grounded in skills from evidence-based treatments for suicidal behavior, with an emphasis on prevention programming for young people. A grant from The Fine Foundation seeded research to develop this novel program. The skills taught in the course focus on four core areas: mindfulness, distress tolerance, emotion regulation, and interpersonal effectiveness. With donor support, our hope is that the project improves the mental health and well-being of area young people.

A LOOK INSIDE THE LAB



Amidst a challenging federal funding environment, UPMC Children's researchers depend on charitable gifts

Research stands at the very center of nearly every advance made in modern medicine. Yet, funding for medical research remains uncertain at best; unattainable at worst. According to a 2018 article published by StatNews, National Institutes of Health (NIH) research funding has steadily declined since 2003. With fewer NIH applications funded, and fewer still going to younger, less established researchers, many budding scientists are opting out of the research field, choosing to pursue more lucrative career pathways.

Unfortunately, these challenges are occurring during an exciting time in medical research. Now, perhaps more so than at any other time in our history, scientists are poised to leverage a growing knowledge of the human genome and recent advances in drug development to make groundbreaking findings that could change the field of medicine forever.

Bridging the gap

In a highly competitive federal research funding environment, bold ideas and novel theories are often overlooked in favor of more predictable, incremental studies. Yet, importantly, significant medical discoveries are only made when dedicated researchers have access to the resources necessary to investigate new, untested hypotheses. In these instances, private donations can make the difference.

Right now at UPMC Children's, our investigators are working on more than 550 scientific projects — many of which are funded through philanthropy. Some of this funding comes from large philanthropic investments like

the Tull Family Foundation's grant to the Richard King Mellon Institute for Pediatric Research at Children's, an important incubator for progressive pediatric research — itself founded through a transformational 2007 gift from the Richard King Mellon Foundation. Yet, other funding comes through individual contributions and unrestricted gifts made by the tens of thousands of Pittsburghers who give generously in support of the hospital's greatest needs.

Whether you rounded up at the register this year, called in to the DVE Radiothon, or attended an event in support of our kids, know that you, too, contributed to UPMC Children's research program. For this, we thank you.

An introduction to our innovators

From world-renowned experts in their field to young scientists just getting started, researchers at UPMC Children's run the gamut. Some perform basic science studies focused on microscopic cell components; others conduct translational projects that span the space between bench and bedside, and others still, tackle clinical and community-based projects looking at large patient groups and whole populations.

So join us now as we introduce you to just a few of the many talented Children's scientists poised to uncover the next big breakthroughs in pediatric health. And as you do, note that despite their apparent differences, these researchers have one thing in common: they all wish to change outcomes for kids in need. With your support, they're doing just that.



Kelly Bailey, MD, PhD

Assistant Professor, University of Pittsburgh School of Medicine

Does immunotherapy help to halt the spread of Ewing's sarcoma?

There was one patient, in particular, who significantly influenced Dr. Kelly Bailey's career. When she was a fellow at the University of Michigan, Dr. Bailey met a 15-year-old diagnosed with Ewing's sarcoma, a type of bone cancer that primarily affects teens. Tragically, the cancer had spread throughout the patient's body, with more than 50 lesions covering his organs. The prognosis was almost certainly terminal.

Yet, somehow, after only three months of chemotherapy, the young man showed no evidence of disease. The physicians were stunned. How had such an aggressive cancer responded so quickly to treatment? Inspired to learn more, Dr. Bailey turned to research.

A physician-scientist in Children's Division of Hematology/Oncology, Dr. Bailey studies how

immunotherapy might be used in combination with traditional chemotherapy to better treat relapsed or metastasized Ewing's sarcoma. With funding from charitable partners, including Hyundai Hope on Wheels, John G. Rangos, Sr., the Children's Trust, and CureRock, she's achieved some promising initial results, identifying a potential inhibitor that might block the spread of the cancer cells.

Sadly, Dr. Bailey's patient back in Michigan lost his battle with the disease earlier this year at the age of 20. But he continues to inspire her work.

With this patient never far from her thoughts, Dr. Bailey hopes to get to the bottom of that question that so intrigued her years ago. Thanks to donor support, she gets a little closer every day.

Deirdre Nolfi-Donagan, MD

Assistant Professor, University of Pittsburgh School of Medicine

Can a better understanding of platelets lead to improved therapies for patients with sickle cell disease?

Deirdre Nolfi-Donagan, MD, is fast. She talks quickly, moves quickly, and even does her research at high speed.

Dr. Nolfi-Donagan treats patients with sickle cell disease (SCD), a genetic condition affecting critical blood flow and leading to painful episodes.

With a generous grant from the Children's Trust, she is conducting a study on platelets, the sticky blood cells that help to form clots. Patients with SCD are far more prone to dangerous clotting, yet traditional anti-clotting medications do not work for them. And Dr. Nolfi-Donagan wants to understand why.

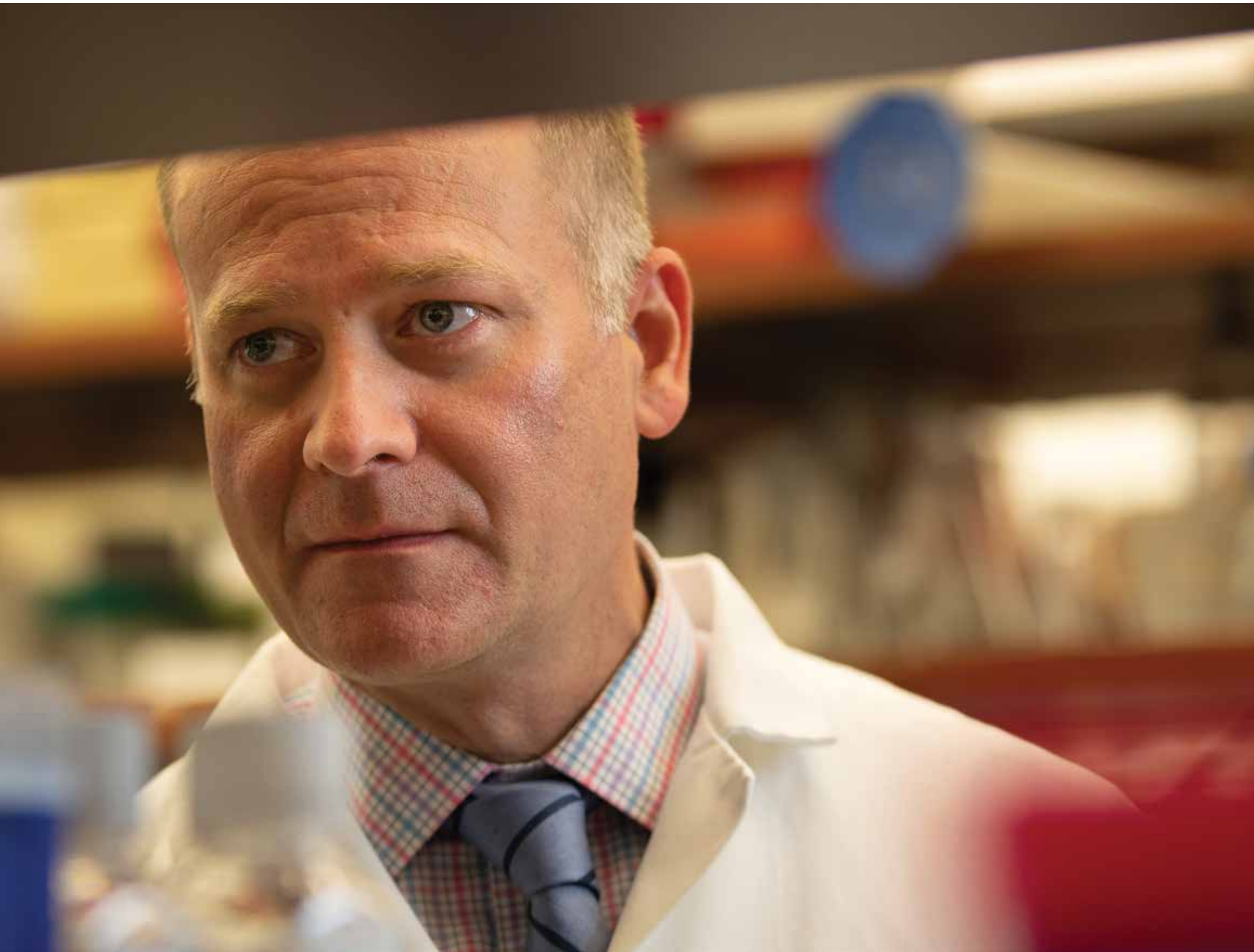
To do so, she has to move fast. Dr. Nolfi-Donagan compares the

platelets of patients with SCD against those of healthy volunteers. The catch is that for her study question, platelets can only live outside the body for four to six hours, tops.

So Dr. Nolfi-Donagan has precious few hours to transport blood samples from the clinic to the lab for study. In that brief time, she's trying to figure out how the platelets become activated to cause a clot — with a hunch that it has something to do with a protein called HMGB1.

"I would run to the lab in the middle of the night if need-be," she shares. "There's a lot of work to be done to improve therapies for patients battling sickle cell disease."





Kevin Mollen, MD

Surgical Director, Inflammatory Bowel Disease Center, UPMC Children's Samuel P. Harbison Assistant Professor of Surgery, Department of Surgery, University of Pittsburgh School of Medicine

Could a simple supplement improve treatment for those living with inflammatory bowel disease (IBD)?

Kevin Mollen, MD, surgical director of the hospital's Inflammatory Bowel Disease Program, understands firsthand what his patients are going through. That's because when Dr. Mollen was only 15, he was diagnosed with inflammatory bowel disease (IBD).

In an attempt to better understand the disease that affects him and a growing number of people worldwide, he has devoted his career to serving those with IBD, both in the clinic and the lab.

Dr. Mollen's research examines the molecular processes at play in the intestinal cells of patients with IBD. With funding from the Richard King Mellon Institute for Pediatric Research and the NIH, he and his collaborators were the very first to identify a fundamental defect

in the mitochondria (the power source of cells) of IBD patients.

Their data suggest that altering the metabolism of these cells with new therapeutics, dietary modification, or even an inexpensive over-the-counter supplement, may trigger the mitochondria to function better. In disease models, the introduction of one such supplement actually reduced inflammation caused by IBD — a promising discovery!

In the near future, Dr. Mollen expects to test mitochondria-targeted treatments in clinical trials. "It's rewarding to think that we can improve care for the very patients we see in the clinic," he affirms. "Research allows us to change lives."

Dwi U. Kemaladewi, PhD

Assistant Professor of Pediatrics, University of Pittsburgh School of Medicine

Are novel genetic technologies the key to correcting a faulty gene in patients with muscular dystrophies?

Assistant Professor of Pediatrics Dwi Kemaladewi, PhD, only joined UPMC Children's in 2019. Yet, already she's making a name for herself. With a big smile and contagious enthusiasm about her work, it's easy to understand why.

Appointed a Mellon Scholar by the hospital's Richard King Mellon Institute for Pediatric Research and a recipient of a 2019 Children's Trust grant, Dr. Kemaladewi has built a career around investigating pediatric rare diseases. She studies a debilitating, deadly form of muscular dystrophy called muscular dystrophy type 1A (MDC1A). Kids with MDC1A have mutations in the LAMA2 gene that cause their muscles and other bodily functions to shut down. Children diagnosed with MDC1A lose the ability to walk, and sadly, many do not make it to their teens.

Dr. Kemaladewi and her colleagues wondered whether they could improve therapies for patients with MDC1A using genetic technologies. So, they set to work studying a gene called LAMA1. LAMA1 is closely related to LAMA2, but only active in utero. Using cutting-edge CRISPR gene-editing, Dr. Kemaladewi and her collaborators "switched on" LAMA1 in mouse models with MDC1A.

The results? Amazingly, the mice given the therapy demonstrated markedly improved motor function and decreased paralysis!

While more work needs to be done, Dr. Kemaladewi is characteristically optimistic. "Generating new scientific knowledge is endlessly rewarding," she grins. "But ultimately, I just want to be able to help these kids and families."





Elizabeth Miller, MD, PhD

*Director, Division of Adolescent and Young Adult Medicine and Medical Director of Community and Population Health, UPMC Children's Hospital of Pittsburgh
Professor of Pediatrics, University of Pittsburgh School of Medicine*

How do we give young people the skills needed to reduce violence and encourage healthy relationships?

Dr. Liz Miller is a world-renowned expert on sexual and partner violence who has been working to improve the lives of vulnerable youth for more than two decades.

As a trained anthropologist, Dr. Miller has a deep appreciation of social theory — one that shapes nearly every aspect of her work.

While Dr. Miller and her team of about 20 researchers and staff have many active studies in the works, they're particularly excited about a new program testing the effectiveness of gender-specific support groups for middle schoolers who have experienced trauma. Expect Respect partners with 36 middle schools throughout southwestern Pennsylvania, with the hope of preventing violence through education and support.

The team is also measuring the success of a high school-based program called Creating Peace. Set in 24 Pittsburgh neighborhoods with concentrated disadvantage, the study addresses gender and racial injustice through group discussions between students and law enforcement officers.

With a staggering number of projects on her plate, including clinic work, mentoring, and teaching, Dr. Miller is nothing if not busy. But she's quick to point out that she doesn't do any of it alone.

Again, with an anthropologist's perspective, she shares, "The schools, service providers, and local foundations are critical partners in our research. None of it would be possible without the community."

Tim Hand, PhD

Assistant Professor of Pediatrics and Immunology
Director, University of Pittsburgh Gnotobiotic Core
Richard King Mellon Institute for Pediatric Research

What if we could harness the healing properties of breastmilk to help prevent disease in newborn babies?

Mellon Scholar Tim Hand, PhD, explains complex bacterial colonization processes as though he were describing what he had for breakfast.

“Your intestines are filled with more than 200 kinds of bacteria, right?” he asks. “And yet, by age 3, most of our bodies have somehow figured out how to discriminate good bacteria from bad — building a healthy bacterial environment in the process.”

Dr. Hand’s research centers on the microbiome, the trillions of bacteria, viruses, and fungi that inhabit almost every part of the human body and play a critical role in many bodily functions.

In a recent study, he and his collaborators discovered that IgA,

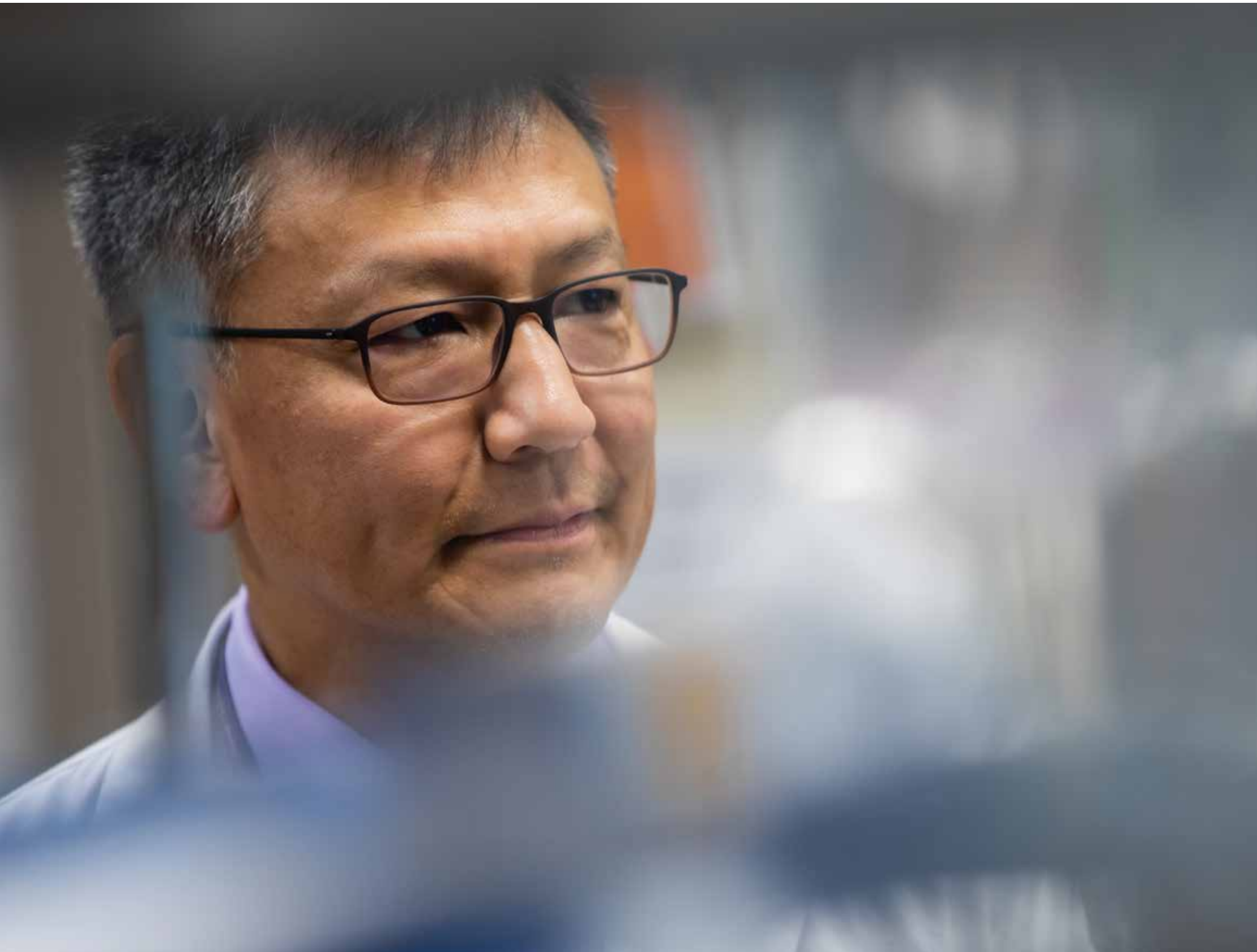
an antibody found in breastmilk, is key to balancing the gut biome. The IgA binds to bad bacteria in the infant’s gut, freeing the gut up to grow more good bacteria and helping to prevent a serious disease in premature babies called necrotizing enterocolitis (NEC).

In the years to come, Dr. Hand hopes to identify the most protective components in human milk to potentially develop a therapy down the line for the babies most at risk.

And when asked if philanthropy plays a role in his work?

“Oh, for sure!” he responds in that down-to-earth way of his. “I couldn’t do this study without the Mellon Institute support. It’s been transformative for me.”





Robert S. B. Clark, MD

*Vice Chair for Pediatric Critical Care, Department of Critical Care Medicine
Associate Director, Safar Center for Resuscitation Research
Professor, Critical Care Medicine and Pediatrics, University of Pittsburgh*

Can big data help to prevent the long-term effects of brain injury?

Dr. Bob Clark cares for some of our hospital's sickest patients: kids in the Pediatric Intensive Care Unit (PICU). And he worries, perhaps most, about those with brain injuries.

Dr. Clark first took an interest in these kids when he was a research fellow at the University of Pittsburgh's Safar Center for Resuscitation Research, a pillar for translational science that relocated to the John G. Rangos Sr. Research Center in 2017.

He trained with the Safar Center's current director, Patrick Kochanek, MD, MCCM, and its founder, the late Peter Safar, MD. Often called "the Father of CPR," Dr. Safar established the center to promote methods of saving lives and reducing disability from trauma and cardiac arrest.

"Here, there are no silos. Scientists at the Safar Center work across a broad spectrum of fields to contribute to resuscitation medicine," Dr. Clark shares.

So in addition to partnering with his fellow physicians, Dr. Clark works closely with information technology specialists to improve outcomes for children with brain injuries. Right now, he and his collaborators are building on UPMC Children's existing electronic surveillance platform to develop a system that employs big data and artificial intelligence to monitor a child's brain health in real time. Using tens of thousands of clinical variables pulled directly from the Electronic Health Record (EHR), the system will automatically alert caregivers when a child is at risk for neurological distress so that early interventions can be administered.

"We want to save lives and increase patients' quality of life," Dr. Clark says. In partnership with a whole host of collaborators, he's advancing the mission of the Safar Center and helping many very sick children and adolescents in the process.

MEET A FEW OF OUR HEROES

To give in support of others is nothing short of admirable. And to do so for the benefit of sick and injured children is particularly heroic. In 2019, a total of 40,978 donors gave to Children's Hospital of Pittsburgh Foundation. That's 40,978 community members like you who contributed to our hospital to change the lives of kids in need. Allow us now to introduce you to just a few of these special heroes:



The Banks Family • When they lost their energetic 10-year-old son, Ben, in late 2017, the Banks family was determined to honor his memory by investing in something he loved: cars! Marie and Ben established the Ben Banks Jr. Toy Car Fund to purchase Hot Wheels and related items for kids at UPMC Children's. According to the family, their hope is that the toy cars given to kids in Ben's name will brighten their spirits as they did his.



Michael Degnan • After living in various cities all over the world, business leader and philanthropist Michael Degnan relocated to the Pittsburgh area for work. And he wants every child in his adoptive city to have access to the most advanced medical care available. "Children's represents the best the 'Burgh has to offer," he shares. "I'm happy to do my part to give back to the city I now call home."



The Vockleys • As chief of Children's Division of Medical Genetics, Dr. Jerry Vockley has devoted his career to kids and families battling rare disease. So, too, has his wife and Children's genetic counselor, Cate Walsh Vockley. The Vockleys contribute financially to Children's Hospital of Pittsburgh Foundation to make a difference in the lives of those they serve. "We have always believed strongly in donating our time, talent, and treasure for others," the couple shares. "Our Children's Circle of Care giving allows us to provide for our patients' medical concerns, while also supporting the needs of their families."



Robert and Kathleen Lee • Robert and Kathleen Lee donate to the Down Syndrome Center (DSC) at UPMC Children's in memory of their beloved daughter, Maria. When Maria was first diagnosed, there were very few resources available for families of kids with Down syndrome. But the Lees eventually connected with the talented physicians and staff at the DSC — who were understanding, attentive, and who cared for Maria all throughout her adult life until she passed away at age 50. Grateful for the support Maria received, Robert and Kathleen give to ensure that others affected by Down syndrome can access this same compassionate care.



The Haller Family • Amy and Ed Haller joined the Children's Trust in 2016. As a physician assistant, Amy has always had a deep appreciation for the regional and national impact of UPMC Children's. But it wasn't until their own son, Henry, was seen here as a newborn baby, that the couple experienced firsthand the devastation that the parents of a sick child face. To help other families in crisis, and in gratitude for Henry's good health, the Hallers give to advance exceptional patient care and research.



The Weiner Family • Aviva Katz, MD, served UPMC Children's Hospital as both a pediatric surgeon and ethicist, touching the lives of thousands during her career. Following her death in 2018, Aviva's husband, UPMC Children's pulmonologist Dr. Daniel Weiner, and children, Sam, Gabe, Shoshana, and Channah, established the Aviva Katz Program in Pediatric Ethics Fund to honor her legacy. Daniel shares, "The program will ensure that Aviva's life's work is continued, helping patients, families, and staff for many years to come." To contribute to Aviva's fund, please visit: givetochildren.org/aviva.

THE MANY INNOVATIVE WAYS YOU GIVE

Our many wonderful donors never cease to amaze us!

From spinathons to stache bashes, and everything in between, Children's Hospital of Pittsburgh Foundation donors continue to come up with creative ways to fundraise in support of the hospital. Check out just a few of the many innovative ways supporters like you make a difference:



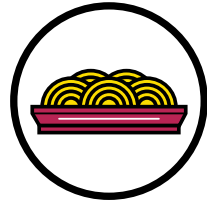
The Ballet Academy of Pittsburgh

You might remember that the classic *Nutcracker* ballet is about a brave young girl with big dreams. It seems only fitting, then, that when The Ballet Academy of Pittsburgh started collecting donations at their annual recital of the holiday classic, they thought of the many courageous patients at UPMC Children's. The talented dancers at The Ballet Academy continue to raise the barre year after year — turning, pliing, and leaping their way to funds that support our hospital's core mission.



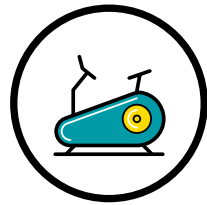
Nathan Carlsen NCM Fundraiser

The Nathan Carlsen NCM Fundraiser honors the life of a Palo Alto fifth-grader who battled Neurocutaneous Melanocytosis (NCM), a rare form of brain cancer. After Nathan's tragic passing in 2018, his family and friends rallied together to fundraise in support of NCM research. And amazingly, they've collected more than \$65,000 to date! This funding supports Dr. Miguel Reyes-Mugica's efforts to collect and study NCM tissue here at UPMC Children's to advance therapies for kids like Nathan.



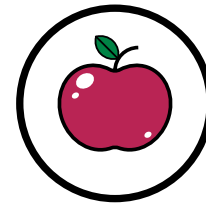
CHLOE Project Spaghetti Dinner

Pittsburgh natives Diane Mottiqua and Joseph Gourley understand firsthand what it's like to have a child in the hospital. The Brooklyn-based couple's 4-year-old daughter, Chloe, has experienced three open heart surgeries in her four short years. Fortunately, when the family needed help most, their friends and loved ones responded — with pasta! The now-annual CHLOE Project Spaghetti Dinner raises money for the Forever Fund, providing direct financial assistance to heart patient families.



6YCLE Sixer Thon

Last winter, 6YCLE spin instructors warmed muscles and spirits alike when they hosted their first annual Sixer Thon to raise funds for Children's Hospital of Pittsburgh Foundation. Starting at 12 a.m. and going for six hours straight, 20 teams of six cycled through the night to a sum of \$17,000. With high-energy classes, free giveaways, and fun games in the mix, instructors kept their Sixers focused on the fundraising goal at hand — spinning their way into our hearts in the process.



Triple B Farms

The Beinlich family has made their farm a destination spot for southwestern Pennsylvanians for decades. Triple B Farms in Monongahela offers sustainably grown produce and family-friendly events like apple picking and fall festivals. This past year, William Beinlich decided to draw on the generosity of Triple B customers as he collected change at the register to benefit Children's. A heart patient himself, William wanted to give back to the hospital that has given him so much. Now, how 'bout them apples?



American Airlines PIT Base Car Cruise

When you hear American Airlines, you might not think about cars. But classic vehicles are precisely how American Airlines team members fundraise for Children's Hospital of Pittsburgh Foundation each year. With all kinds of cool cars outside the hangar, the PIT Base Car Cruise celebrates American Airlines staff while giving back to the greater Pittsburgh community — steering thousands of dollars towards our hospital's greatest needs.



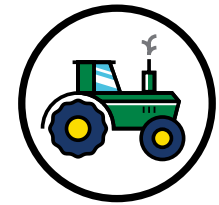
UPMC Children's Residents' Stache Bash

When the pediatric residents at UPMC Children's heard about the chance to fundraise for Children's Hospital of Pittsburgh Foundation several years ago through No Shave November, they were all in. The residents — men and women alike — throw an annual Stache Bash, a contest to see who can grow (or knit) the coolest, weirdest mustache. This past year alone, the hair-raising event brought in several hundred dollars in support of Pennies from Heaven, a fund that helps families with hospitalized children.



Samantha Giordani's Survivorship 5k

College student Samantha Giordani considers herself a survivor. When she was in fifth grade, Samantha was diagnosed with cancer. She was treated here at UPMC Children's, and thankfully, Samantha is now cancer-free. Grateful for the treatment she received, Samantha decided to host a 5K fundraiser this past year in support of the hospital's SurvivorConnect™ program. Our thanks to Samantha for running for a good cause.



Devi's Annual Tractor Ride

Every October, Lexie and Bill Mills join with friends and family to host a tractor ride in Vanderbilt, Pennsylvania in honor of Devi Matthews, who passed away in March 2015. All are invited to come out to the Franklin Township Community Park for a 10-mile tractor and wagon ride, hog roast lunch, kids' pedal tractor pull, and prizes! Thanks to a dedicated community of supporters and participants, Devi's Annual Tractor Ride has raised thousands of dollars for Children's Hospital of Pittsburgh Foundation each year since 2015.



Justice4Joi

When 2-year-old Justice Joi was only hours old, she was rushed to the Neonatal Intensive Care Unit (NICU) at UPMC Children's for care. She was here for nearly a month — her parents and two big sisters left to balance life between the hospital and their family home in Ohio. But thanks to the care she received, Justice Joi is now thriving. In 2018, her family established the Justice4Joi organization, raising funds to support NICU patients and spreading joy to other families in need.



One of the 5,200 participants who helped raise more than \$846,000 at this year's Walk for Children's

HIGHLIGHTS & FEATURES

Why We Walk

The fourth annual *Walk for Children's* saw the event's biggest turnout to date, with over 5,200 walkers making the trek through Schenley Park on June 1. Patients, families, and more than 25 community sponsors began the day at Flagstaff Hill, where they danced, sang, played games, and celebrated stories of healing and hope. Through the Kohl's Hard Heads Helmet Program, our generous partners at Kohl's Cares even gave out free helmets with Children's Safety Center. Decked out in medals and bright purple shirts, over 240 Patient Champions then led the parade on that clear, sunny day, walking to raise over \$846,000. Every dollar raised supports the brave kids and families receiving care at UPMC Children's.

Another Great Year for Telethon

In its 66th year, the annual KDKA Free Care Fund Benefit Show raised over \$1.739 million in support of the Free Care Fund for UPMC Children's. Broadcasting live from the hospital's Eat'n Park Atrium and Howard Hanna Healing Garden, the event featured three junior hosts, all patients at UPMC Children's. Each

year, thousands of children benefit from the Free Care Fund, which provides families from our region with free and uncompensated care. In 2018 alone, the fund helped to offset the cost of care for more than 35,500 kids.

Shake and Shimmy for UPMC Children's

This year's Pitt Dance Marathon (PDM) raised a record-breaking total of \$338,609. Supported by sponsorships from Ace Hardware and All of Us PA and a generous gift (and surprise appearance!) from Steelers wide receiver JuJu Smith-Schuster, the Pitt students who spearhead this annual event brought its lifetime fundraising total to more than \$1 million. Other schools are catching the dance fever as well. Carnegie Mellon University raised \$4,853 during its first ever Dance Marathon, and numerous local high schools danced till they dropped to raise money for UPMC Children's.

The Votes Are In!

UPMC Children's continues to be named among the best. *Parents* magazine recognized Children's

as one of the Most Innovative Children's Hospitals in the nation for excellence in research led by Alejandro Hoberman, MD, around improved medical therapy for ear infections. Our hospital was also named on Soliant Health's 2019 list of the Top 20 Most Beautiful Hospitals, voted seventh in the nation. And the Human Rights Campaign Foundation recognized the hospital's proactive efforts to improve the patient experience for LGBTQ+ kids and teens, naming Children's a "Leader in LGBTQ+ Healthcare Equality." We're humbled to be in such good company.

Pillar of the Community

UPMC Children's Division of Community Health works with local schools and service providers to reduce disparities, increase wellness, and elevate quality of life for kids and families in the communities where they live, learn, work, and play. Through a range of initiatives like Healthy Schools, an evidence-based program that helps schools create a culture where healthy eating, physical activity, and trauma sensitivity is simply the norm, the division strives to improve outcomes for the many families who call western Pennsylvania home.



Michele Michaels and "Princess" Lilli at the 12th annual DVE Rocks Children's Radiothon

HIGHLIGHTS & FEATURES

A Critical Hit for our Kids

Gamers everywhere are rallying together in support of kids in need by participating in Extra Life — a worldwide fundraising and gaming marathon for their local Children's Miracle Network Hospital. For 734 Pittsburgh-based gamers, this meant dedicating an entire day of play to raise funds for UPMC Children's. Some all-star participants include Pittsburgh Knights eSports Team, Children's patient Maddox Hyde, and Schell Games. Through board games, cards, and video game marathons, this gamer army raised a record-breaking \$163,000 to help our kids beat their injury or illness. In the gaming world, we call that a critical hit!

Rockin' at Radiothon

We celebrated a record-breaking year for the 12th annual DVE Rocks Children's Radiothon, which raised a grand total of \$886,825 to support the patients and families being treated at UPMC Children's. With 408 energetic volunteers, 1,095 listeners who called in to give, and 31 generous sponsors — Radiothon is truly a team effort. And of course, it wouldn't be possible without Randy Baumann,

Bill Crawford, Val Porter, and Mike Prisuta of the 'DVE Morning Show, Michele Michaels, and Chad Tyson. Rock on, guys. Rock on.

Cardiac Collaborations

UPMC Children's is proud to partner with Wolfson Children's Hospital of Jacksonville, Florida in an effort to elevate and expand specialized cardiac care for kids in the southeastern U.S. In addition to collaborating in cardiac surgery services, UPMC Children's cardiologists will support patients, families, and caregivers in Wolfson Children's Cardiovascular Intensive Care Unit via telemedicine. Key partnerships like this one are helping to make exceptional care more accessible to the kids and families who need it most.

Catching the Cure

In 2018, Steelers wide receiver Ryan Switzer began fundraising for UPMC Children's, based on how many catches he made per football game. The challenge resulted in a grand total of \$18,000 raised to support cancer patients here at our hospital. In 2019, he did it again, personally pledging \$40 for every

catch made during the 2019-2020 season. In a city of champions, Ryan makes us proud to be from Pittsburgh.



We're in the Top 10

UPMC Children's was recognized as one of the top 10 pediatric hospitals in the country on the *U.S. News & World Report* ranking of Best Children's Hospitals. Our hospital also ranks among the top 10 children's hospitals for all five of our pediatric subspecialties: cardiology and heart surgery (third), diabetes and endocrinology (sixth), gastroenterology and gastroenterology surgery (seventh), pulmonology (sixth), and urology (tied for tenth). And how fitting that the year we celebrate our tenth anniversary on the Lawrenceville campus, we are honored among the 10 best hospitals in the nation.



CMNH Pittsburgh Patient Champion Gabriel

HIGHLIGHTS & FEATURES

Care on Wheels

In partnership with Ronald McDonald House Charities of Pittsburgh and Morgantown, UPMC Children's has been providing free medical care to underserved communities for the past 18 years through the Ronald McDonald Care Mobile — a fully staffed "doctor's office on wheels." In fall 2019, the Care Mobile team debuted a brand-new, 40-foot mobile unit featuring two exam rooms, a lab, and intake area. Thanks to this fantastic philanthropic partnership, kids who might be otherwise unable to come to our hospital for care can receive "care on the go!"

Helping the Whole Family

Physicians, nurses, and specialists here at Children's recognize that for a child to attain good health, his or her basic needs must be met. To attempt to improve families' access to food and other necessities, the Division of Community Health turned to philanthropy. In partnership with the Henry L. Hillman Foundation, the division implemented a screening initiative to gauge patient families' food insecurity with a simple, evidence-based two question survey,

providing assistance and warm referrals when needed. Through additional private donations, they further established the Basic Needs Fund to distribute grants directly to vulnerable families.

Taking a Stand Against Childhood Cancer

Alex's Lemonade Stand Foundation (ALSF) is dedicated to changing the lives of children with cancer by funding research, raising awareness, and supporting families. For the past ten years, ALSF has been a critical partner to Children's. And this year, the foundation is at it again, offering a generous match grant in support of our hospital's Clinical Oncology Research Program. ALSF will match up to \$62,500 to help bring the newest and most promising pediatric cancer therapies to our kids. How very sweet.

Great Job, Gabriel!

Our very own UPMC Children's patient Gabriel Tillman was recently named the Children's Miracle Network Hospitals (CMNH) Pittsburgh Patient Champion. CMNH partner Marriott hosted a champion kick-off event in

February, welcoming Gabriel along with the outgoing and past CMNH champions and families. As Patient Champion, Gabriel proudly represents Pittsburgh in person and on social media, encouraging donors to support our hospital so that kids like him can find hope and healing. This is an incredible honor, and we couldn't ask for a better advocate.

Cam we do it? Yes we Cam!

UPMC Children's has found an incredible philanthropic partner in The Heyward House — a foundation started by Steelers defensive end Cam Heyward in 2015. This past year, The Heyward House teamed up with Edgar Snyder & Associates to provide clothing, school supplies, and transportation for kids and families receiving care at UPMC Children's Child Advocacy Center (CAC). The Heyward House additionally contributed a generous grant to the CAC to help kids in crisis. And Cam and his team also hosted a magical holiday visit, spending an afternoon in the Eat'n Park Atrium handing out jerseys and Terrible Towels, meeting and chatting with kids, families, and staff alike. You're the man, Cam!



A special night for campers at this year's Camp Chihopi

HIGHLIGHTS & FEATURES

Raise Your Glass

More than 250 people came out to Narcisi Winery on August 6 for the eighth annual unWINEd: A Toast to Hope for a Cure. Glasses were raised in honor of all the kids and families battling pediatric cancer at UPMC Children's. Event chairs Tiffany Casarcia and Debbie Depew were thrilled to raise nearly \$250,000 this year, benefiting the Division of Pediatric Hematology/Oncology and the Division of Blood and Marrow Transplantation. Now, we raise our glasses in thanks to Tiffany, Debbie, and all the community partners who make this possible!

Beards are Shaved, Lives are Saved

Former Steeler and fan favorite Brett Keisel hosted the ninth annual Shear Da Beard at Jergel's Rhythm Grille in February, rallying Steelers fans and raising vital funds for the cancer program at UPMC Children's. The lively, sold-out crowd enjoyed music, a special guest appearance from Cam Heyward, and of course, the official shearing of the beard. Together, fans and donors raised a total of \$181,203, all to support kids battling cancer at our hospital.

Here's to our Miracle Makers

Walmart and Sam's Club have been great fundraising partners for Children's Miracle Network Hospitals (CMNH) since 1987, and this year, they officially surpassed their \$1 billion milestone! This incredible feat is the culmination of numerous donations, including gifts made at the register, auctions, potlucks, and other family events spearheaded by store associates. The 2018 U.S. campaign reached a grand total of \$30 million, with \$500,000 raised locally to benefit UPMC Children's. Hats off to our awesome partners at Walmart and Sam's Club.

Star-Studded Support

Children's Hospital of Pittsburgh Foundation was honored to be one of the beneficiaries of the 2019 HM3 Celebrity Care Fest — an exciting fundraising event generously hosted by the HM3 Partners Independent Fund. VIP guests enjoyed live performances by Chicago and Peter Frampton. Ticket proceeds benefited the Whole Child Wellness Clinic at UPMC Children's — a new initiative aiming to elevate and streamline care for kids with complex behavioral health needs.

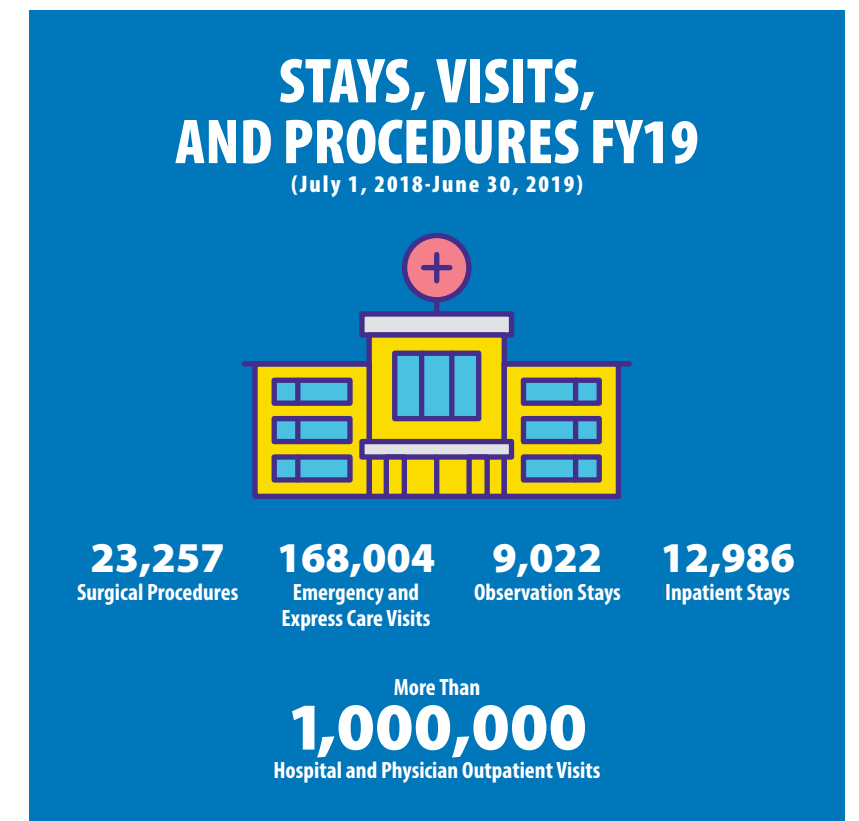
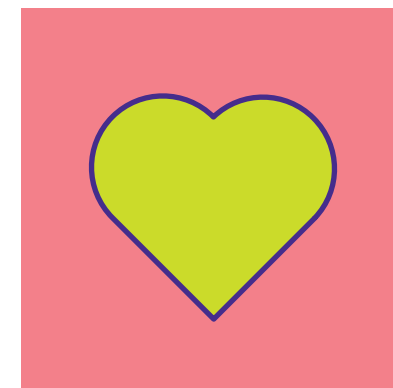
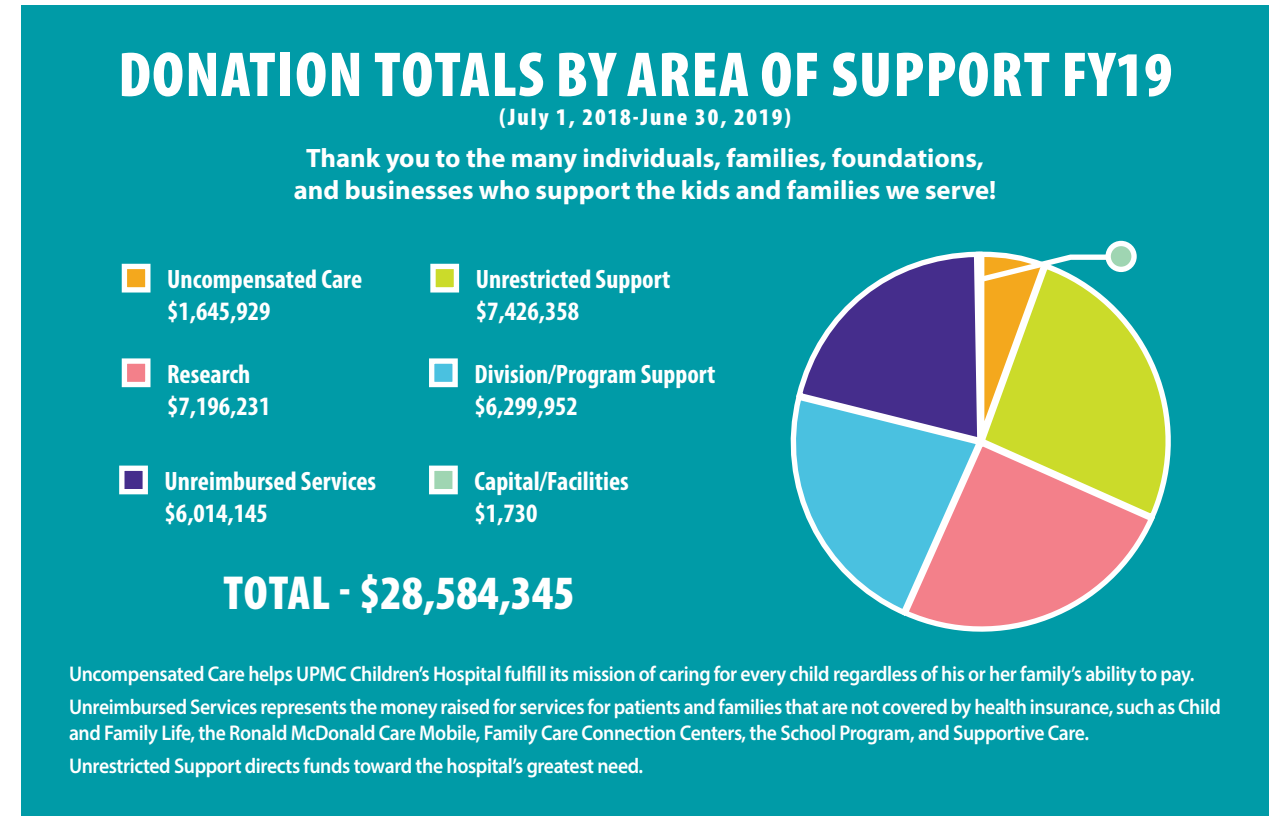
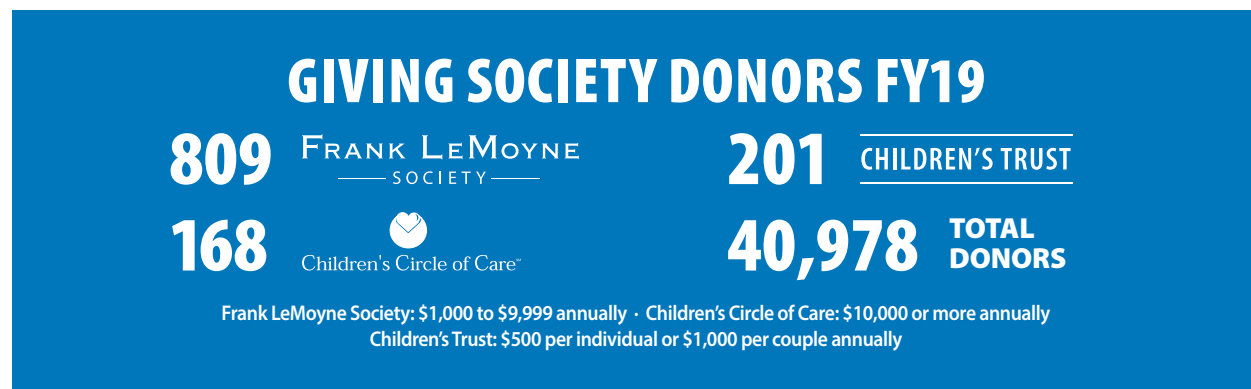
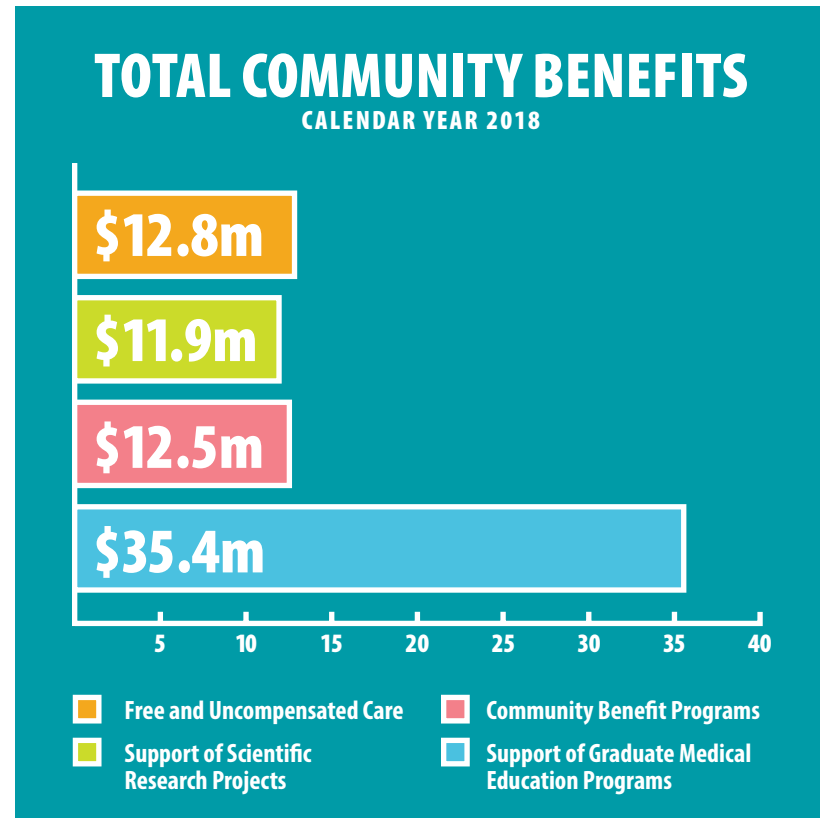
Good Ole Summertime

Thanks to the philanthropy of many generous donors, UPMC Children's hosts numerous summer camps for patients and families each and every year. These camps provide all the fun and adventure of a traditional summer camp experience, but in safe, supportive environments for kids with a variety of medical, social, and emotional needs. These include Camp INSPIRE (tracheostomies, ventilators, and BiPAP machines), Camp Chihopi (transplant), Camp STAR (youth amputee), Camp Wakchazi (sibling bereavement), Heart Family Camp, and finally, the Dr. Bill Neches Heart Camp for Kids — which will celebrate its 30th anniversary in 2020!

BY THE NUMBERS

Your contributions enable us to accomplish amazing things! As a nonprofit organization, UPMC Children's Hospital of Pittsburgh depends on the generosity of supporters like you to provide charity care for families who can't afford treatment and to subsidize community-focused programs and services.

With your support, we reinvest resources back into our local community, providing these total community benefits.



Welcome Aboard!

Both Children's Hospital of Pittsburgh Foundation and UPMC Children's Hospital of Pittsburgh are steered with passion, integrity, and a sense of community service by dedicated Boards of Trustees.

These volunteers dedicate their time, energy, and expertise into helping us improve the health and well-being of our region's kids and families. Whether through advocacy, fundraising, or planning for the future, our trustees are committed to ensuring that UPMC Children's Hospital is here to serve the community for many years to come.

The Foundation is pleased to welcome two new members to its Board of Trustees, both of whom bring a wealth of knowledge, experience, and personal commitment to keeping our hospital on the cutting edge of pediatric health care.



Kelley Skoloda, MBA
Founder and CEO
KS Consulting & Capital LLC

Kelley Skoloda is the founder and CEO of KS Consulting & Capital LLC. She is also a co-founding member of the Next Act Fund, an angel investing organization. Her most recent investment is in a company that develops medical devices for pediatric cardiac use. Previously, she was a partner and director of the global brand marketing practice for Ketchum. Her cause marketing work was recognized globally with a Cannes Gold Lion Grand Prix award for the Whirlpool "Care Counts" campaign. Kelley's business book, *Too Busy to Shop: Marketing to Multi-Minding Women*, was named a "must read" by Publishers Weekly. She was named one of the "most influential women in business" by the Pittsburgh Post-Gazette and voted into the PRSA-Pittsburgh Hall of Fame. She also served on the BlogHer/SheKnows and Women@NBCU advisory boards and the Seton Hill University board of trustees, and as a member of The TODAY Show Parenting Network.



Gregory J. Weimer
Partner
Confluence Financial Partners

Gregory J. Weimer has been guiding clients in the management of their wealth since 1986. He is a partner and co-founder of Confluence Financial Partners, where he strives to set a new standard for the financial services industry. He earned his business degree at the University of Pittsburgh with concentrations in computer science and mathematics. Greg began his career as a financial advisor at Butcher & Singer, then moved to CNL Securities Corporation in 1989 and then to American Funds in 1993, where he was appointed senior vice president and served on the board of directors. Greg also served as Vice Chairman of the Washington City Mission, and he was nominated for the Leukemia & Lymphoma Society's 2019 Man of the Year. Greg and his wife, Lori, have four children and two granddaughters.

UPMC Children's Hospital of Pittsburgh Board of Trustees

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Children's Hospital of Pittsburgh Foundation Board of Trustees

As of December 31, 2019

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Children's surgical patient Jake enjoys time with a Pet Friends therapy dog



Top: Children's patient Tayden; Bottom: Hannah, patient battling cancer





Children's surgical patient Amber



Children's
Hospital of Pittsburgh

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