

FALL ISSUE 2021

CHILDREN'S CONNECTION



Meet Riley Gutierrez!

A little girl with a big smile and unwavering strength.

Page 3



For the Friends of Children's Specialized Hospital Foundation

Foundation President's Message



The best part of being in the CSH family is the people I get to meet, serve and work with.

— PHILIP SALERNO III —

CSH Foundation President & Chief Development Officer

Dear Friends,

In prior issues you may recall me saying that for me, the best part of being in the Children's Specialized family is the people I get to meet, serve and work with as part of the Foundation. Today, I write with mixed emotions as I think of several key volunteers we lost over the last 12 months and in contrast I am excited to welcome Dr. Matt McDonald as the new President and CEO, Dr. Colin O'Reilly as Vice President and Chief Medical Officer, and Kelly Keefe Marcoux as Vice President of Patient Care Services and Chief Nursing Officer.

A few months ago, one of our long time trustees, volunteer leaders, auxiliaries and friends, Lynn Kolterjahn, passed away. She was just the most recent loss following other wonderful friends including Janet Jackson, Brucie Talcott and Jean McDermott. Each of these women shared a commitment to our hospital, our patients and one another. They truly personified servant leaders. No task or request was ever too small or too big. I can't recall any of them ever saying "no" when I asked for their help. They asked about my sons as I asked about their children, grandchildren and eventually great grandchildren. They were truly part of the fabric of who we are and what we do each day.

In speaking with Rich Ahlfeld, who served as President here for 26 years, we agreed that Lynn, Janet, Brucie and Jean were the "greatest generation" when it came to volunteers. While they are deeply missed, their presence can be felt on a daily basis by those of us fortunate enough to have known them.

In fact, it is their legacy of leadership and service that each of us carries forward every day. It is for this reason that I share my excitement about Matt, Colin and Kelly's new roles at CSH. Each of them have been with Children's Specialized for several years and are well steeped in the culture of our hospital. Each has a laser like focus on doing everything possible to improve the lives of the children we serve. Amazingly, Dr. McDonald is the first physician to take the role of CEO in our 130 year history! As we look at expanding our reach to serve more families throughout the state and region, we are fortunate to have their fresh perspectives, outlook and energy guiding us.

Be sure to read the profiles on each of them to learn more about the newest members of the dynamic leadership team here at Children's Specialized.

All the best,



03: COVER STORY

After surviving a hemispherectomy at only 11-months-old, **Riley Gutierrez** is on a journey to recovery.

06

Meet the CSH Foundation TCS NYC Marathon Team

07

Chronic Illness Management Program is Changing Lives

09

CSH is Expanding into Monmouth County

12

Walk n' Roll Marks Its 15th Year

IN THIS ISSUE

Dr. Matt McDonald is Primed to Design the Next Generation of Care as Children's Specialized Hospital's New CEO

Matthew B. McDonald III, MD was appointed President and Chief Executive Officer of Children's Specialized Hospital (CSH) in June. Dr. McDonald joined the CSH team in 2014 as Section Chief of Special Needs Pediatrics and, while in this role, he guided a multidisciplinary team to develop the first National Committee for Quality Assurance (NCQA) certified medical home in New Jersey for children with special healthcare needs and medical complexities. In addition, he led the expansion of CSH's second Special Needs Primary Care location in Hamilton, NJ. In 2016, Dr. McDonald became the President of the Medical Staff at CSH and in October 2017 he was appointed Associate Vice President and Medical Director of Outpatient Services before taking on the role of Vice President and Chief Medical Officer in June 2018. Most recently, Dr. McDonald served as Senior Vice President and Chief Medical Officer taking on more responsibilities within the CSH and RWJBarnabas Health system.



"During his tenure at CSH, Dr. McDonald has distinguished himself as a thought leader and steadfast advocate for children with special healthcare needs and their families," said Barry Ostrowsky, President and CEO, RWJBarnabas Health. "His leadership will be pivotal in driving Children's Specialized Hospital and RWJBarnabas Health forward as the preeminent provider of pediatric healthcare in New Jersey."

Dr. McDonald's professional mission is parallel to that of Children's Specialized Hospital's—to improve the care delivered to all patients through access, education, innovation and partnerships. Through his vision, he has led many projects that serve to redefine and expand how medical professionals treat children with special healthcare needs.

"As we embark on an era of expansion, I couldn't be more pleased to have Dr. McDonald as the new President and CEO of Children's Specialized Hospital," said Fred Tewell, CSH Board of Trustees Chair. "His experience and unique perspective will be great assets as we design the next generation of specialized pediatric care."

Dr. McDonald's leadership will serve to enhance and expand access to CSH's nationally recognized programs for families with special healthcare needs across New Jersey and beyond.

"I feel truly blessed to live what I love every day and I'm thrilled by the opportunity to lead the CSH family," said Matthew B. McDonald III, MD, President and CEO, Children's Specialized Hospital. "With the help of the CSH Foundation and the generous support of our donors, we will continue to meet the unique needs of children and young adults with special healthcare needs by enhancing access to our exceptional programs and services. Improving the quality of life and health outcomes for our patients and their families is my life's calling. You have my commitment that I will be relentless and purposeful in our efforts to deliver the care and culture required for every one of our patients to reach their full potential." ■

“

*As we embark on an era of expansion,
I couldn't be more pleased to have
Dr. Matt McDonald as the new
President and CEO of
Children's Specialized Hospital.*

”

— FRED TEWELL —

Chair, Children's Specialized Hospital Board of Trustees

She May Be Small, But She is Mighty

After what Breezzye Weir describes as an amazing pregnancy, her daughter, Riley Gutierrez, was born in December 2018. Shortly after she was born, a port-wine stain was noticed on Riley's face and arm, and she was quickly taken to the Neonatal Intensive Care Unit (NICU) where she stayed for three weeks to undergo testing. "At first, the doctors ruled out diagnoses like Sturge-Weber Syndrome so we figured she had a birthmark and took her home. But at three months old, she had her first seizure."

Following that terrifying night, Riley was back in the Pediatric Intensive Care Unit (PICU) where she spent a week undergoing more testing and evaluations. The medical team performed an MRI on Riley and this time her progressive vascular disorder showed up clear as day—she was promptly diagnosed with Sturge-Weber Syndrome.

Sturge-Weber Syndrome is a rare progressive disorder characterized by the facial port-wine birthmark, neurological abnormalities, and eye abnormalities, although some patients may only develop one or two of these symptoms. "The results were clear that our baby had this malformation in her blood vessels causing abnormal blood flow and blockage to the left side of her brain, which affected the right side of her body, causing the seizures," shares Breezzye.



in October she experienced her worst seizure to date and it was clear that further intervention was necessary.

In November 2019, at only eleven months old, Riley was admitted to the hospital once again, this time to undergo a scheduled hemispherectomy. Performed in children who experience severe and uncontrollable seizure disorders, a hemispherectomy is a neurosurgical procedure in which half the brain is removed, disconnected, or disabled.

After the procedure, Riley was transferred to Children's Specialized Hospital's (CSH) Inpatient Facility in New Brunswick for rehabilitation. "I was praying that we would be able to get her in there," shares Breezzye. "I was familiar with the hospital, Riley's grandmother is actually a nurse practitioner there, so I knew about the amazing treatments and therapies that they provide. They see miracles every day and I knew that would be the best place for Riley."

After surgery, Breezzye lived in the hospital with Riley for the next few months, which allowed her

“

*They see miracles at CSH every day
and I knew that would be the
best place for Riley.*

”

— BREEZZYE WEIR —
Riley's Mom

With a confirmed diagnosis, Riley was put on anti-seizure medications but every six weeks she would experience another seizure causing her to end up back in the hospital. In July 2019, it had been almost three months since Riley had experienced a seizure—the longest span of time without a seizure since her diagnosis—and she was doing well. But

to receive all the care and rehabilitation she needed. “It was a great experience. The staff was wonderful and even though we had to spend her first birthday in the hospital, everyone there made sure it was celebrated and special for her.”

Riley’s comprehensive inpatient treatment plan included occupational therapy, speech and feeding therapies, and physical therapy. Her physical therapist, Alex, shares that they utilized aquatic therapies, functional electric stimulation, bracing, knee immobilizers, standers and gait trainers, along with therapy sessions with our facility dog, Burton.

Additionally, much of Riley’s occupational therapy included working on age appropriate self-care activities like pulling off socks and self-feeding during mealtimes. “Riley is such a sweet little girl,” shares occupational therapist, Danielle. “She loved snuggles and whenever she was tired, she would just snuggle up on your lap and let you know it was time for a break.”

For speech therapy and feeding therapy, Riley worked with her therapist specifically on expanding her diet and accepting more solid foods. By the end of her stay, she had relearned how to eat puree solids, was continuing to work on her chewing and learned how to drink through a straw. “Initially she was not turning her voice on, but as time went on, she was making some babbling sounds and waving during sessions. She was also reaching for toys and definitely full of smiles,” shares her speech language pathologist, Alexandria.

In February 2020, Riley was able to go home. “I’m so grateful for just moving forward this year. Even with the COVID-19 pandemic and being under quarantine, I was grateful I was home with my baby and able to spend time with her,” said Breezzye.

Today, Riley continues to visit CSH for outpatient therapy, including occupational and physical therapies, feeding therapy, early intervention and speech therapy. “Our entire apartment is not only kid-friendly but is set up so we can incorporate what she’s doing in therapy at home in between sessions as best as we can,” shares Breezzye.

Riley also worked with the Rehabilitation Technology team at CSH and recently received her very own gait trainer and custom supportive seat. “Mary and the entire team were great to work with. We received Riley’s custom gait trainer in October. That feeling of watching her stand for the first time was so meaningful—it changed everything.”

Breezzye shares that outings used to be very cumbersome and would be a source of anxiety for both her and Riley, “She hated being in the stroller. She wanted to get out and

“

That feeling of watching her stand for the first time was so meaningful—it changed everything

”

— BREEZZYE WEIR —
Riley’s Mom



Riley is so happy feeling free to move around on her own!

explore and now with her gait trainer, she is able to be more interactive and engaged. She’s so happy feeling free to move, to walk!” Recently Breezzye and Riley went on an outdoor outing and Riley was able to feed some animals at the petting zoo.

Being home and continuing her outpatient treatments at CSH has helped Riley to continue hitting milestones, “when she first came home, she could barely hold her head up on her own. Now she can scoot around the living room on her own! I keep saying, it’s amazing what a year will do!” ■

5TH ANNUAL OPEN A SUCCESS



Open committee co-chairs, Denise Porter and Eric Jensen, address more than 160 golfers in attendance.

On June 21, Children's Specialized Hospital Foundation hosted their Fifth Annual Open at Metedeconk National Golf Club in Jackson, NJ with over 160 supporters in attendance. The event raised a record-breaking **\$260,000** for Children's Specialized Hospital (CSH) and the life-changing care provided to thousands of children each year.

"After a year full of uncertainty, seeing everyone together was truly heartwarming," said Philip Salerno III, President and Chief Development Officer at CSH Foundation. "I am so very grateful to all who came out and helped us break a fundraising record for this event!"

Among the many guests, CSH patients, Carly Decker, Leah Hansen, and Luca Damas, were in attendance to share their miraculous stories of rehabilitation and recovery and thank the golfers for their support.

"As co-chair of this event committee for many years, I am so thankful for all of the committee members who gave selflessly of their time to make this year such a success," said Denise Porter. Eric Jensen, Open committee co-chair, added, "We're also appreciative for the support of the golfers who show up every year not only for an exquisite day of golf, but to help us raise a tremendous amount of money for the hospital. We're looking forward to 2022!"

Golfers included representatives from many New Jersey businesses who are long-time supporters of the hospital and truly believe in the vision of creating a world where all children can reach their full potential.

Top sponsors of the event included Rendina Health Care Real Estate, Hammond Contracting, Michael Riesz & Co., Langan Engineering and Environmental Services, Breaker Electric, Highland Associates, Alan and Penny Blake, and PSE&G. ■

HOSPITAL NEWS

Dr. Colin O'Reilly Appointed Vice President and Chief Medical Officer



We are pleased to congratulate Colin O'Reilly, DO, FAAP, FACOP, FCCP, on his recent appointment as Vice President and Chief Medical Officer at CSH. Dr. O'Reilly joined the CSH team in 2015 and in this new role, he will support the overall clinical vision of CSH

and provide medical oversight, expertise and leadership to ensure the highest quality and most compassionate care for our patients and their families.

Kelly Keefe Marcoux Appointed Vice President and Chief Nursing Officer



Kelly Keefe Marcoux, MSN, CPNP-AC, PPCNP-BC, CCRN-K, has been appointed Vice President of Patient Care Services and Chief Nursing Officer at CSH. Ms. Keefe Marcoux, an integral part of the CSH staff since 2014, will support the provision of patient

care services in the rehabilitation hospital, long term care units, ambulatory sites and community programs. Additionally, she will oversee patient safety as well as nursing practice and standards throughout CSH. Congratulations, Kelly!

CSH Expands to 15 NJ Facilities

We are excited to announce that Saint Barnabas Medical Center's (SBMC) Pediatric Rehabilitation Services will now be managed by Children's Specialized Hospital (CSH).

CSH will be overseeing the clinical and operational responsibilities of SBMC's pediatric physical, occupational, and speech therapy programs, integrating the specialized services that CSH has been known for in New Jersey and beyond for 130 years.

This West Orange outpatient facility will serve as CSH's 15th facility in New Jersey, providing another access point for our current families and a new community of children and families who may need our services.

RUNNING WITH A MISSION



Children's Specialized Hospital Foundation is thrilled to be participating once again in the TCS New York City Marathon Official Charity Partner Program. With eight runners committed to raising funds to support the life-changing care at Children's Specialized Hospital (CSH), this year promises to be particularly special—the TCS New York City Marathon, taking place on November 7, will be celebrating its 50th running of the marathon!

"Supporting charitable causes and organizations are a long-standing tradition of the TCS New York City Marathon as it serves as one of the world's largest fundraising platforms," said Christine Burke, Senior VP of Strategic Partnerships, NYRR. "The marathon exemplifies the running community's spirit of giving back, and no group demonstrates that more than the thousands who choose to run for charity. We are proud to support the efforts of the CSH Foundation team and the positive impacts they have made in their community."

"The dedication of this team of runners, training for many months through sometimes extreme weather conditions, is incredibly inspiring," said Philip Salerno III, President and Chief Development Officer, CSH Foundation. "Their resilience and strength is mirrored in the patients we serve and we are incredibly grateful they chose to help further our mission by raising awareness and funds while pursuing their passion."

Meet some of our runners:

Sarah Zavala, a pediatric audiologist, started running five years ago, "I love working with children and I'm excited to be running my first marathon and honored to be racing with the team supporting Children's Specialized Hospital."

Michael Crompton is running his third marathon! "I am running the 2021 TCS NYC Marathon so that more and more children will be able to take that first step, like patient Leah Hansen, as a result of the care they received at Children's Specialized Hospital. I am looking forward to not only completing my third marathon, but being able to do it for the kids so that ALL children can reach their full potential."

Steve Hudson is training to run his first marathon. He has a special connection to CSH through his wife, Nicole, who dedicated over a decade to raising funds for CSH. "She poured her heart and soul into doing what she could to give the kids at CSH the absolute best care and attention they deserve. Seeing the stories of perseverance from these kids overcoming what they have to face is humbling, and training for a race to raise a little extra money for them is the least I can do to contribute."

Ian Massaroni is looking forward to the challenge of running his first marathon, "I'm excited to be a part of the Children's Specialized Hospital Foundation team as it is an incredible cause to support. Through friends and family, I have seen the toll major health struggles can take on kids—the work CSH has done for 130 years is truly life changing for kids who have to go through such hard times."

Teresa Dziob works at JackRabbit in Westfield, NJ and has been running for 15 years, but this is her first marathon! She is so excited to be running for CSH Foundation, "I personally find great joy in running for a cause that gives hope and joy to children going through a very difficult time!"

SUPPORT OUR RUNNERS!

To support Children's Specialized Hospital
TCS NYC Marathon 2021 Charity Team
please visit <https://bit.ly/CSHFCharityTeam>.



CSH CHRONIC ILLNESS MANAGEMENT PROGRAM **CHANGES KIDS' LIVES**

A teenager living with juvenile diabetes, Ashley Augusty was experiencing many episodes of diabetic ketoacidosis, a serious condition that can cause diabetic coma or even death. It was critical that she learn to manage her diabetes properly at home to maintain her health and live life to her full potential. After her fourth hospitalization in just one year, Ashley was transferred to Children's Specialized Hospital (CSH) to complete the Chronic Illness Management Program (CIMP) and learn the life skills she needed to live a healthier life with her medical condition.

Ashley is just one of many children in the United States living with a chronic illness. In fact, approximately 27% of children in the U.S. are living with a chronic health condition and one in 15 has multiple chronic conditions.¹ CIMP at CSH is specifically designed for kids living with chronic, life-altering conditions like diabetes, cystic fibrosis, HIV/AIDS, sickle cell, heart disease, autoimmune disorders, metabolic disorders, organ transplants and others.



The program typically includes a four-week inpatient stay during which children are taught about their disease with classroom style education while being educated through real life experiences and healthy habit formation. The children work closely with all members of multidisciplinary teams, including a certified diabetes educator, a nutrition specialist, a psychologist, medical personnel, and physical, occupational, recreational, and child life specialists,



incorporating what they are learning into practice. Bedside nurses are always there to reinforce the education as well.

Family members are required participate in their child's educational and psychological sessions to explore how the chronic disease has affected the family unit and work towards ways to allow the child and family to reach their full potential. **Children who complete CIMP inpatient care and follow up with outpatient care are significantly more independent at managing their medical condition when they return to their routines at home.**

"Our Pediatric Chronic Illness Management Program is unlike any other program in the United States. It is truly unique," said Dr. Colin O'Reilly, Vice President and Chief Medical Officer at CSH. "Families are guided through the process from referral through follow up clinic by our program navigator. We focus on improving 'total health' targeting the mind, body, and spirit connection—if you don't focus on all aspects of a disease you may be missing the mark."

Dr. O'Reilly continued, "One of my favorite things about this program is seeing the children interact together—

some children with type 1 diabetes have never met others their age with the same disease. When they come to our program, the sense of isolation that they have experienced goes away. It is impressive to see. Our clinical outcomes and data from the program have been incredibly positive and the impact of this program has now been recognized nationally.”

Ashley credits Children’s Specialized Hospital for not only changing her life, but for saving it. She reflected on her experience in CIMP at CSH, saying, “Children’s Specialized Hospital helped me a lot because they gave me a lot of tools for basic living. This was the only hospital that gave me examples of real-life situations. For example, they took me out to a lot of chain restaurants and taught me how to count carbs and take my medicine when you’re with friends and you might not want to.”

With such high numbers of children under 21 living with chronic illnesses in the United States, including more than 280,000 individuals aged 20 and under living with diabetes, continuation and expansion of this program is an important part of our commitment to respond to the greatest healthcare needs of

“
We focus on improving total health targeting the mind, body and spirit connection— if you don’t focus on all aspects of a disease, you may be missing the mark.
”

— DR. COLIN O’REILLY —
CSH Vice President and Chief Medical Officer

children. BD (Becton Dickinson), a global medical technology company with headquarters in Franklin Lakes, NJ, recognized the importance of CIMP for children living with chronic illnesses and awarded the CSH Foundation a \$35,000 grant to support it.

Linda Hrevnack, Manager of Social Investing for BD, says that the company’s philanthropic support of CIMP aligns with its commitment to finding innovative ways to address unmet healthcare needs and improve healthcare access—right here in its headquarters state of New Jersey, and around the world.

“BD is grateful to Children’s Specialized Hospital for its commitment to helping local children better understand how to manage juvenile diabetes, so they can be empowered to live long, full and healthy lives,” said Hrevnack.

CSH Foundation works to secure philanthropic support for vital hospital programs and services, like this one, so children have access to the care they need to reach their full potential. For over 130 years, CSH has been responding to the greatest needs of children and CIMP is just one example of the specialized care that makes an enormous impact on the quality of life for children living with special healthcare needs. ■

1. https://www.cdc.gov/pcd/issues/2015/14_0397.htm#:~:text=Approximately%2027%25%20of%20children%20in,this%20population%20have%20been%20limited



CSH IS EXPANDING ACCESS TO CHILDREN IN MONMOUTH COUNTY

For 130 years, CSH has been responding to the most urgent healthcare needs of children—actively working toward the ambitious vision of a world where all children can reach their full potential. Earlier this year we announced the construction of our new outpatient facility in Union, NJ and now we are pleased to announce that we will be bringing our renowned outpatient services to a new population of children in Monmouth County as part of the brand new RWJBarnabas Health Family Care & Wellness Center.

Together with Monmouth Medical Center (MMC), CSH broke ground earlier this year on the new building located at the Monmouth Mall in Eatontown. CSH will occupy 15,000 square feet of this new 82,000 square foot, four-story medical and wellness center providing medical services including developmental and behavioral services, psychiatry, neurology and physiatry. Additionally, CSH will offer a full range of therapy services including audiology, speech language, occupational, physical and psychology.



special healthcare needs. **We have seen exponential growth in the number of children who require specialized care and have consistently responded by expanding our services into new communities to give more children convenient access to care.**

The generosity of CSH Foundation donors has been instrumental to the growth and development of CSH over the last 130 years. With philanthropic support, CSH has grown to be the preeminent provider of pediatric rehabilitation services in the United States and is currently the largest regional provider of autism services. Many children treated at CSH are living with multiple life-long medical conditions—from chronic illnesses like diabetes, brain and spinal cord injuries, and complications from premature birth like cerebral palsy to a full scope of developmental, behavioral and mental health concerns including autism and ADHD.

Philip Salerno III, CSH Foundation President and Chief Development Officer talks about this latest CSH expansion, saying “This is an exciting time to be part of the CSH story as the next generation of care for children with special healthcare needs unfolds. We have seen first hand how philanthropic support of hospital programs, services and initiatives has positively impacted the lives of thousands of children and families in our communities. Our support of this expansion into Monmouth County will bring hope and healing to many more families who currently don’t have access to the kind of specialized care CSH delivers.” ■

“

We’re introducing ourselves to patients and families who need our services but were previously unable to access them.

”

— DR. MATTHEW B. MCDONALD —
President & CEO, Children’s Specialized Hospital

“We’re thrilled to bring CSH’s innovative programs and services to Monmouth County,” said Matthew B. McDonald III, MD, President and CEO, Children’s Specialized Hospital. “This period of expansion is so exciting for CSH because we’re introducing ourselves to new patients and families who need our services but were previously unable to access them. With every new patient we meet and care for, our vision of a world where all children can reach their full potential gets that much closer to reality.”

Since the beginning, CSH has been a success story in progress—continually building on past accomplishments to break barriers and enhance the lives of children with

A SPECIAL THANK YOU TO OUR DONORS

Children's Specialized Hospital Foundation is proud to acknowledge the generous support of our donors. We are pleased to recognize the following donors who supported us with major gifts between **February 1, 2021 and August 31, 2021.**

Visionary Society (\$500,000+)

- Anonymous
- The Alan J. and Pendryl G. Blake Fund
- Jay and Linda Grunin Foundation
- Costco Wholesale

Benefactor Society (\$250,000+)

- The Westfield Foundation

Leadership Society (\$100,000+)

- Pinky and Neel Shah

Humanitarian Society (\$50,000+)

- Karma Foundation
- Estate of Alfred A. Moser

Founder Society (\$25,000+)

- Anonymous
- American Pile and Foundation LLC
- Thomas and Lynne Cross
- Elecnor Hawkeye LLC
- Eii, Inc.
- Furino & Sons, Inc.
- Goldman Sachs Gives
- Jingoli Power, LLC
- Asif Khan
- Becton Dickinson and Company

- Dr. Heinz K. Hofmeister
- PSE&G Corporation
- Alexander R. Giaquinto, Ph.D.
- J. Fletcher Creamer & Son, Inc.
- Joseph Jingoli & Sons, Inc.
- Burns & McDonnell Engineering Co.
- Henkels & McCoy, Inc.
- Haugland Energy Group LLC
- Timothy J. Piazza Memorial Foundation

Cornerstone Society (\$10,000+)

- Anonymous
- Autoland
- Black & Veatch
- The Carian Group Corporation
- CMC Energy Services, Inc.
- The Cornell Finance Company
- DNV Energy Services USA Inc.
- E.J. Grassmann Trust
- Extra Life/Microsoft
- Angelo Fiorito Trust
- Grampy's Charities Gives
- Michele Hall-Duncan
- Harlan Electric Company, Inc. (MYR Group)
- IFC Consulting Group, Inc.
- Johnson & Johnson Consumer Products Company

- Kean University Center for Leadership and Science
- Cynthia and John Kirchner
- Estate of Adelaide C. Kroeger
- Hess Corporation
- Matrix NAC
- McPhee Electric
- Merck Company Foundation
- MSPC
- New Jersey Institute of Technology
- NJ State Council Sheet Metal Workers International Association
- C. Northrop and A. Marder Pond Foundation
- Panda Restaurant Group, Inc.
- Estate of Ruth B. Petersen
- RE/MAX, LLC
- RE/MAX Diamond Realtors
- Michael Riesz & Co., Inc.
- John Jr. and Michael Rohall Jr. Foundation
- Philip Salerno III
- Sargent & Lundy, LLC
- Stevens Institute of Technology
- Toyota Dealer Match Program
- Walmart of New Jersey
- Young Management & Consulting



MAKE A BIGGER IMPACT WITH A MONTHLY GIFT!

100% OF EVERY DONATION
SUPPORTS THE LIFE-CHANGING CARE & CUTTING-EDGE
RESEARCH AT CHILDREN'S SPECIALIZED HOSPITAL.



scan to
give now

<http://bit.ly/cshf-news>

PSE&G'S 10TH ANNUAL GOLF OUTING SOARS TO NEW HEIGHTS



From left to right—Philip Salerno III (CSH Foundation President and Chief Development Officer), Danita Fox (P&C Division Administrator at PSE&G) and Victor Viscomi (PSE&G Senior Director and member of CSH Foundation Board of Trustees)

PSE&G hosted its 10th annual Vendor Golf Outing to benefit Children's Specialized Hospital Foundation on August 30th at Fiddler's Elbow Country Club in Bedminster, NJ and had another record-breaking year, raising more than **\$575,000!**

Guest speaker, Olivia Lopes, shared the story of her son LJ's remarkable journey of rehabilitation and recovery at CSH after he was struck by a car at just seven months

old. Her moving story illustrated the importance of the specialized care provided at CSH, bringing the mission to life for more than 260 golfers in attendance.

"I am blown away by the show of support for our 10th Annual Vendor Golf Outing. To raise \$575,000 for the kids is just amazing," said Vic Viscomi, PSE&G Senior Director and member of the CSH Foundation Board of Trustees. "PSE&G's commitment to CSH began almost 20 years ago and this event has been an incredible opportunity to introduce our vendor partners to the mission and vision of the hospital and give them the chance to make a difference in the lives of local children."

"This event is just one example of PSE&G's dedication to enhancing the lives of New Jersey's children," said Philip Salerno III, President and Chief Development Officer at CSH Foundation. "We turned to PSE&G in 2003 and explained our vision of creating a better world for children living with special healthcare needs. Since then, they have been steadfast partners, committed to supporting the Foundation in our efforts to secure philanthropic support for the life-changing care at Children's Specialized Hospital." ■

“

I am blown away by the show of support for our 10th Annual Vendor Golf Outing. To raise \$575,000 for the kids is amazing!

”

— VICTOR VISCOMI —

PSE&G Senior Director & CSH Foundation Board of Trustees

15TH ANNUAL WALK N' ROLL HONORS CSH HEALTHCARE HEROES

Honoring Our Healthcare Heroes

The CSH staff are heroes to their patients every single day, but their commitment to their work and patients during the COVID-19 pandemic was extraordinary. It was that expression of passion and dedication that led the CSH Foundation to recognize the entire CSH staff as the 2021 Walk n' Roll honorees.

Each and every staff member made significant adjustments to minimize the disruption of care for our medically fragile patients. Everyone—from doctors, nurses and therapists to administrative, environmental services and kitchen staff—made the necessary changes to keep the kids at CSH safe. Therapists adapted to Telehealth quickly, developing creative ways for their patients to continue making progress at home. The environmental and security teams implemented new safety protocols in an effort to keep COVID out of our facilities. Administrative staff switched to a virtual work environment and kept operations running smoothly.



To honor the staff, the CSH Foundation invited patient families and supporters to leave a message for their heroes on an e-card, featured a photo gallery during the Walk n' Roll livestream, and presented them with small tokens of appreciation. As an added treat, the Walk n' Roll registration sponsor, **RE/MAX Our Town - The Baricaua Group** surprised our New Brunswick staff with free ice cream from Mr. Softee on Walk n' Roll day!

You can honor the CSH Healthcare Heroes today by donating to the Walk n' Roll!

Visit www.childrens-specialized.org/walk.

SIGN THE E-CARD FOR CSH HEROES

Scan code below or visit
<https://bit.ly/CSHWishYou>



WATCH THE VIRTUAL WALK N' ROLL

Scan code below or visit
<https://bit.ly/WNRLiveStream>



Kimberly Pena Named 2021 Walk n' Roll Patient Ambassador

Kimberly Pena survived five brain surgeries in 2020 to become a first-generation college graduate in her family this year! Her story of strength and resilience was so inspiring that we chose Kim as our 2021 Walk n' Roll Patient Ambassador.

"We are thrilled to have Kim serve as our patient ambassador this year," said Philip Salerno III, President & Chief Development Officer at CSH Foundation. "Kim is a true champion who displayed extraordinary strength and courage in the face of tremendous medical challenges. Her story of resilience reminds us why it is important to support Children's Specialized Hospital and the life-changing work done here."

When Kim was diagnosed with a **cerebrospinal fluid leak (CSF)**, her condition was critical and she underwent five brain surgeries to repair the leak and subsequent complications that followed her surgery. **Because Kim needed specialized therapy to regain muscle control and learn to walk and talk again, she was transferred to the experts at Children's Specialized Hospital** in September 2020 where she received intensive neurological, physical and occupational therapy to help her heal.

Kim's occupational therapy helped her with day-to-day living and she received speech therapy work in both English and Spanish.

Her therapy was intense, but she powered through it all. Kim reflected on her journey saying, "Serious health issues transform everything in your life—from the plans you may have had for a random Tuesday to the goals you were working toward. Being transferred to CSH was the best thing that could have happened to me. They helped me get better—not just physically, but mentally, emotionally and socially, too."

An avid writer, Kim journaled daily. Her writing was therapeutic and helped keep her positive & confident throughout the demanding healing process.

After a month, Kim regained much of her strength, and the Neuro Rehabilitation Therapy Care team helped her shift from inpatient to outpatient status.

Today Kim is doing great. She has completed her bachelors degree in sports management, becoming a first generation college graduate in her family! ■



PATIENT UPDATE

CHRISTIAN PANARESE NEVER GIVES UP



After bringing home what the Panarese family thought was a healthy baby boy, they soon realized that Christian Panarese had some complications. At six-months-old, Christian cried 23 hours a day. After a visit to the pediatrician left his grandmother, Nancy, without answers, she sought the advice of a pediatric orthopedist that referred Christian to Children's Specialized Hospital (CSH).

Diagnosed with **Hydrocephalus Quadriplegia (born without the entire right side of his brain)**, Christian began physical, orthopedic, speech and augmentative therapy at CSH in Mountaintop. He also received rehab-tech services to assist with his mobility.

Christian always loved setting goals during his therapy sessions. A student in the Westfield school system, Christian looked forward to one day eating lunch with his class. He once had a goal to learn how to eat Doritos! When he started therapy at CSH he could not sit up, drink or even hold a cup. As Christian progressed in therapy, he was eventually able to eat, drink and hold a cup with his right hand.

Rehabilitation was not easy for Christian. He was unable to speak and often cried during his therapy sessions. His greatest success was at seven and a half years old when he spoke for the first time.

Nancy recalls being extremely angry when first coming to CSH and taking her frustrations out on staff. Through their patience and kindness they were able to teach her how to take care of Christian *and* address *her* needs. Nancy says that the kindness of CSH staff is a gift that she will always cherish.

"When we started therapy at CSH, I was not happy and did not want to be there," said Nancy. "However, we came to therapy for 15 years and in all those years we were always treated with respect, compassion and understanding."

Now age 22, Christian is no longer a patient at CSH but he still uses the tools that he learned there every day. He relies on a wheelchair and has limited use of his left arm, but that hasn't stopped him from achieving his goals. Christian graduated from the Westfield school system where he studied graphic arts, business and cooking through the vocational program.

"Christian is always smiling and happy, he has a wonderful outlook on life and always remains positive," said Nancy. "Our lives have recently changed dramatically—my husband passed away about a year and a half ago and then COVID-19 hit and we moved into an apartment. We have experienced lots of changes and through it all Christian has remained positive and has helped me get through it all."

She continued, "My hope for Christian is that he will continue to grow and be happy now that he is in another phase of his life."

Nancy is now an employee of CSH and has been part of the Family Faculty for 15 years, Nancy and Christian are now on the "other side" helping new patients and families navigate their own journeys at CSH.

"My advice to other families is to take it one day at a time. Don't beat yourself up if everything is not perfect; just do what you can," Nancy says. "Remember to smile. Have confidence that you and your child have landed in the best place that you can be and be secure in knowing the staff here at CSH will partner with you on this journey."

Christian has had and continues to live a full life. Through the years he has been involved in rock climbing, wheelchair racing, challenger baseball, soccer, swimming, martial arts and sled hockey. He always says with his trademark smile, "Life is tough but I never give up. I keep on going." ■

TOGETHER, WE ARE **MAKING MIRACLES**

Since 1983, often by raising \$1 at a time, Children's Miracle Network Hospitals has funded major programs, projects, research, and equipment for the kids treated at their 171 partner hospitals across North America— including Children's Specialized Hospital, your local Children's Miracle Network Hospital.

Our Children's Miracle Network Hospitals partners go above and beyond to change kids' health.



During the month of May, our local **Costco Warehouses** and their members vowed to #ChangeKidsHealth by raising over **\$704,955** for our patients at CSH!
Thank you, Costco!



Thank you, **Walmart and Sam's Club!** Associates across the country rallied to #ChangeKidsHealth and change the future right in their own communities, raising **\$224,431** for CSH. *We couldn't be more grateful!*

PLAY GAMES HEAL KIDS

extra life
Play Games. Heal Kids.

enormous
Children's
Miracle Network
Hospitals

Join Us **NOVEMBER 6TH** to Play Games & Heal Kids!

Extra Life 2021 will be funding audiology at our new outpatient facility in Monmouth County. Audiology is a vital outpatient service at CSH, providing comprehensive diagnostic evaluations for hearing loss and related issues, such as nerve damage, in infants and children. A child's hearing ability is critically important as they grow because it assists in speech and language development.

Sign up today to help fund this vital service for our patients!

Visit www.extra-life.org and choose Children's Specialized Hospital as your local beneficiary.

Sign up today!





150 New Providence Road
Mountainside, NJ 07092

Nonprofit
Organization
US Postage
PAID
Rahway, NJ
Permit No. 608

OUR MISSION

Children's Specialized Hospital Foundation's mission is to inspire and secure philanthropic support for Children's Specialized Hospital, the preeminent provider of specialized healthcare for children and adolescents facing special health challenges—from chronic illnesses and complex physical disabilities like brain and spinal cord injuries to a full scope of developmental, behavioral and mental health concerns.

Our award-winning doctors, researchers and pediatric specialists work with patients and families in pursuit of the vision of a world where all children can reach their full potential. Children's Specialized Hospital depends on the generosity of donors to discover innovative ways to help more children break barriers and transform their lives.



100% of every donation supports the life-changing care and cutting-edge research at Children's Specialized Hospital.

To learn more about Children's Specialized Hospital Foundation

VISIT:

www.childrens-specialized.org/giving

EMAIL:

foundation@childrens-specialized.org

CALL:

908-301-5561

STAY CONNECTED!



@ChildrensSpecialized



@ChildrensSpecNJ



@ChildrensSpecNJ



Children's Specialized
Hospital