

SPRING ISSUE 2022

CHILDREN'S CONNECTION



Transforming Lives 2.0

Expanding access to children across New Jersey through the largest **Capital Campaign** in our history.

For the Friends of Children's Specialized Hospital Foundation

Foundation President's Message



Looking back, I'm amazed at the pace at which our hospital has grown during my tenure. And that growth is largely due to our incredible family of donors.

— PHILIP SALERNO III —

CSH Foundation President & Chief Development Officer

Dear Friends,

When I first started at Children's Specialized in 1987, the Foundation was not even two-years-old. The medical staff consisted of four physicians and our only site was the one in Mountainside. There were no outpatient programs to speak of then.

The average length of stay was 90 days and 30% of our inpatient population were children who had sustained a traumatic brain injury. We were treating between 200-250 children in a year.

Today, Children's Specialized Hospital is a thriving, growing system of 15 pediatric specialty care sites throughout New Jersey, with more on the way.

The average length of stay has been reduced to about one month. Even during the pandemic, we treated between 35,000-38,000 children. There are nearly three dozen pediatric specialists and sub-specialists on staff supported by incredible teams of nurses, therapists and support staff who all contribute to making our hospital the preeminent provider of pediatric specialty healthcare services in the nation.

And, perhaps most importantly, we have some of the best clinical outcomes in the country. It is sometimes hard to believe that what was once referred to as the hospital on the hill or the best kept secret in New Jersey is now leading the way in enhancing the lives of so many children entrusted to us.

Happy Spring!

Mark Your Calendar For Our 2022 Events

06.20.22
6th Annual
OPEN

METEDECONK NATIONAL
GOLF CLUB
GOLF4CSH.ORG

10.09.22
16th Annual
**WALK
n
ROLL**
FOR CHILDREN'S
SPECIALIZED HOSPITAL
**NEW LOCATION
THIS YEAR!**
COLONIAL PARK, SOMERSET, NJ



03: COVER STORY

Transforming Lives 2.0, the Largest Capital Campaign in Our History, is Underway

Pictured on Cover, The Transforming Lives 2.0 Campaign Cabinet, from left to right:

Jeremy Grunin, George Destafney, Ed McKenna, Matthew B. McDonald III MD, Philip Salerno III, Matt Skurbe, Todd Frazier, and Mark Montenero

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A WARM WELCOME

TO OUR NEWEST FOUNDATION BOARD MEMBERS

The CSH Foundation is pleased to welcome five new members to our Board of Trustees this year. Throughout our history, we have been incredibly fortunate to have passionate leaders on our board who deeply care about our mission. The addition of these five individuals brings new knowledge and experience to our Board that will enhance our effectiveness and leadership as the Foundation continues to grow and meet the expanding needs of the hospital and the pediatric special needs community.



Virginia Ailing is Managing Director, Senior Vice President at PNC Bank N.A. Virginia has an MBA from the College of William and Mary and has built a successful career in corporate finance and investment banking for public and private companies in New Jersey and the New York metropolitan area. She brings with her strong financial background a long history of giving back to the community. Virginia currently serves as chairman of the board of trustees for TechUnited NJ and is currently a board member of the Timothy J. Piazza Memorial Foundation.



Sandy S. Broughton is Vice President Community Development Officer (NJ) at Investors Bank, overseeing the development of community relations activities that help promote the bank's brand in the community. Sandy has more than 30 years of experience in the non-profit sector, holding the role of executive director at the Ocean

County College Foundation and serving on the boards of Fulfill, Child Advocacy Center of Ocean County, and the United Way of Monmouth and Ocean Counties. She is also a member of the Monmouth/Ocean Development Council and the Association of Fundraising Professionals of NJ.



Joe Mindak has over 25 years experience growing several businesses in various industries. He currently runs The Connective with chapters in 5 states and over 100 members. Joe has always been committed to charity, starting with the Big Brother program in college to 10 years in The Rotary Club, United Way and now

the boards of Children's Specialized Hospital Foundation

& Summit Speech School. Joe became involved with the American Legion in Hoboken after Superstorm Sandy and was the catalyst for getting a new legion built in town with six units of housing for homeless veterans. He is currently working on plans to provide homes for at-risk veterans across the country through his own foundation, The Foundation for Sustainable Veteran Housing.



Pinky Shah is Team Leader at Fairway Independent Mortgage Corporation. Pinky has a special connection to CSH because her brother was a patient here when they were children. She has been an avid supporter of our events and a loyal donor for many years. Pinky completed her Pharm D at Rutgers and worked at Johnson & Johnson

before being drawn to the mortgage industry where she felt she could make a direct, long-term positive impact on many people's lives. Pinky has incorporated a cause marketing culture at her mortgage firm and is wholly committed to giving back to her community.



Edward J. Zampella, MD, FAANS (L), FACS is recognized as a leader in neurological surgery in the Northeast and has been recognized as one of New Jersey's "Top Docs" in New Jersey Monthly Magazine for multiple years. Dr. Zampella served as the managing partner of Atlantic Neurosurgical Specialists and is a past president

of the New Jersey Neurological Society. Recently retired from clinical practice, Dr. Zampella has embarked upon a second career as a service line chief for multiple specialties at Summit Health. He was introduced to CSH Foundation by Nick Boccella, current CSH Foundation trustee and former board chair.

TRANSFORMING LIVES 2.0

Today, more than any time before, Children's Specialized Hospital (CSH) Foundation needs our community of supporters to rally together so we can change the future for children living with special healthcare needs. We are currently in the midst of the largest capital campaign in our 35-year history, Transforming Lives 2.0. Once completed, the initiatives funded by this campaign will shape the future of pediatric care in New Jersey—and beyond—and expand our reach to thousands more children.

To date, we have raised just over \$34 million toward our \$45 million goal. Not only will this campaign increase access to care for more children today by funding the opening of four new outpatient centers in Union, Eatontown, Toms River and Bayonne, but by funding critical research, innovation and discovery, it will meet the needs of children in the future.

A Bright Future for Pediatric Long Term Care

Our historic hospital in Mountainside has been the pinnacle of pediatric specialized care and a beacon of hope for local families for the past 131 years. In addition to the outpatient services provided there, CSH Mountainside is also home to 44 medically fragile children whose conditions are too complex to be properly cared for at home. These children are living with mechanical ventilator dependency, complex seizure disorders, neuromuscular disorders, complications of prematurity, terminal illnesses or a variety of other critical conditions. Our Pediatric Long Term Care Center at Mountainside provides a therapeutic atmosphere, specialized medical and nursing care, and a diverse offering of activities designed to provide a loving environment and encourage each child to live to their full potential.

The landmark white "house on the hill" continues to stand proudly in Mountainside, but the remainder of the hospital that has been built around it is undergoing a complete renovation to better serve the needs of our residents in the Pediatric Long Term Care Center. When the renovations at CSH Mountainside are complete, our long term care residents will enjoy a more stimulating, technologically advanced environment that allows them to experience life more fully.

Additionally, the renovations serve the important purpose of expanding the center to house a total of 62 children, offering more families the opportunity to provide their children with the best possible care and quality of life.

"Medical advancements have led to an increase in the number of children living with complex healthcare needs," said Dr. Sheryl Vassallo, Medical Director Long Term Care at CSH. "The addition of more beds within our facility will afford CSH the ability to provide residential and respite care for this unique and growing patient population."

The Transforming Lives 2.0 capital campaign is raising funds for this initiative and CSH Foundation marked the commencement of the renovations with a ceremonial "wall-breaking." CSH and foundation leadership, members of the respective Boards of Trustees, campaign cabinet members and community leaders were given the honor of swinging the sledge hammers to mark the official start of the \$19 million renovations that will enhance the future for the most medically fragile children in our care.



Leslie Logan Taylor, CSH Foundation Board of Trustees Chair, swings sledge hammer at Mountainside ceremonial wall breaking. Looking on from left to right are Mark Montenero, CSH Foundation Board of Trustees, Darielle Walsh and Jay Boyle, Westfield Foundation, and Thomas C. Phelan, Esq.

"The Westfield community is at the core of the Children's Specialized Hospital story," said Philip Salerno III, president and chief development officer at Children's Specialized Hospital Foundation. "This hospital was founded by Westfield residents in 1891 and over the last century their spirit of caring, kindness and generosity has grown, making CSH the nation's leading provider of pediatric rehabilitation treating more than 35,000 children each year."

The Westfield Foundation, a community foundation dedicated to improving the lives of citizens in and around Westfield, awarded a \$300,000 grant to CSH Foundation to kick-off the Mountainside renovations and continue the

2.0 IS IN FULL SWING

commitment of the Westfield community to ensure that children have access to the specialized care they need to reach their full potential.

“

What keeps me up at night are the 200,000 children in New Jersey that we have yet to reach. They all need our services and we need to do our part to make sure that those children have access to our care.

”

— COLIN O'REILLY, DO, FAAP, FACOP, FCCM —

Vice President and Chief Medical Officer, Children's Specialized Hospital

New Outpatient Center in Toms River is a Home Run

In February, CSH broke ground on the site of the new Toms River outpatient center that will open in the spring of 2023. This three-story, 86,000 square-foot medical hub will be shared with Community Medical Center and RWJBarnabas Health Medical Group, with CSH occupying more than half of the space in the building. Once completed, this new facility will bring together the outpatient services currently offered at the CSH Toms River Lakehurst Road and Stevens Road sites to one convenient, state-of-the-art location to better serve our patients.

“Children's Specialized Hospital has a longstanding commitment to children and youth with special healthcare needs,” said Matthew B. McDonald III, MD, President and CEO of Children's Specialized Hospital. “This groundbreaking is a remarkable milestone on their behalf because this facility will afford us the opportunity to better serve the kids in Toms River and surrounding communities.”

Mark Montenero, CSH Foundation Board of Trustees, capital campaign co-chair, president of Autoland Toyota, Jeep, Chrysler, Dodge and RAM Trucks, and Toms River resident addressed the crowd, thanking the community for coming together to support the capital campaign. “This campaign is garnering support from people all over New Jersey,” said Montenero. “We are so appreciative of their generosity that



Todd Frazier, Major League Baseball All-Star and Olympian, his wife, Jackie and son, Grant, join CSH to break ground on new outpatient center in Toms River.

will give thousands more children access to the specialized care they need.”

Community leaders from across the state were also in attendance, including local officials, RWJBH leadership, doctors and leaders from CSH and the partner facilities, and the CSH Foundation Transforming Lives 2.0 capital campaign cabinet. **Todd Frazier**, Major League Baseball All-Star and proud Toms River native, his wife Jackie and their son Grant celebrated with us as part of their role as honorary capital campaign co-chairs.

“When we were presented the opportunity to serve as honorary co-chairs for such an amazing organization, we decided that there would be no better way to give back to our community,” said Jackie Frazier. “The children in Toms River will benefit greatly from this new facility and we are so proud to be a part of bringing them the absolute best care available.”

The lobby of the new Toms River outpatient center will feature an interactive showcase that highlights the life and baseball career of Todd Frazier to inspire all children who enter our doors that they, too, can reach their full potential and achieve their dreams. ■

SPARKING INNOVATION

RESEARCH THAT WILL CHANGE THE FUTURE FOR CHILDREN WITH AUTISM

CSH is at the forefront of pediatric research with more than 50 active studies in the areas of autism, brain injury, chronic illness, cognition and mobility. The **Transforming Lives 2.0** capital campaign intends to raise \$20M to support the Center for Discovery, Innovation and Development (CDID) at CSH, to fund research studies that will design the future of pediatric healthcare.

Research, discovery and development are crucial to providing the highest quality care for children of all ages who are living with special healthcare needs. The Research Center and CDID at CSH often partner with organizations to find innovative ways to treat children with complex medical needs. One such partnership is with SPARK, an online research study that aims to make new discoveries and advance the understanding of Autism Spectrum Disorder (ASD). With over 275,000 participants aged two to 92, SPARK is the largest study of ASD ever and has the ability to study ASD across the participants' lifespan. CSH is one of 17 recruiting centers for SPARK, along with some of the nation's leading research universities and autism centers, making measurable contributions to its success.

The prevalence of ASD has increased significantly over the past two decades. It is estimated that one in 35 children in New Jersey are living with ASD. While there are many different treatments available for children living with ASD, like behavioral therapies, there is not a known single cause. SPARK studies behavioral, medical and genetic information from participating individuals and families to better

understand what makes people unique. The participants play a role in powering autism research for years to come and contribute to the possibility of finding a genetic cause of ASD in the family. Since its launch in April 2016, SPARK has discovered 150 new ASD risk genes and identified a link between ASD and depression and anxiety in adults.

CSH provides a comprehensive approach to treatment for patients with ASD that includes physical, occupational, feeding and nutrition therapies, psychology, speech and language therapy, and an early intervention program. But perhaps, most importantly, CSH offers free early developmental screenings for all children ages one through five, whether they are showing symptoms of ASD or not. While research is important to understanding ASD and guiding treatment plans, identifying ASD in children early is critical to providing the appropriate care so each child can reach their full potential and each family can begin to understand, accept, and better manage their child's behavioral or developmental challenges.

As the largest regional provider of autism services, CSH plays a leading role in the pediatric landscape for enhancing the future for children living with ASD. Since 2019, when CSH joined SPARK, 6,000 CSH patient families have been enrolled in the SPARK study and we continue to promote acceptance by educating the public through webinars, video series, and by sharing our patients' stories.

You can help us change the future for kids living with ASD by donating today at give2csh.org.



IN THE NEWS

CSH Recognized by Newsweek on **World's Best Specialized Hospitals List**

Children's Specialized Hospital has been recognized on Newsweek's list of World's Best Specialized Hospitals 2022. Presented by Newsweek and Statista Inc., the world-leading statistics portal and industry-ranking provider, this prestigious award is given to hospitals considered as leading providers in any given medical sub-specialty. CSH was recognized for our state-of-the-art facilities, having the most accomplished physicians and diagnosticians, and offering the highest level of care

"We are ecstatic to be recognized on Newsweek's list of World's Best Specialized Hospitals," said Matthew B. McDonald III, MD, President and CEO, Children's Specialized Hospital. "Every day, we're privileged to care for children and adolescents facing special health challenges. Our incredible team of pediatric specialists works tirelessly to ensure every one of our patients can reach their full potential, making our many innovative therapies and medical treatments unique to their individual needs. I'm so proud they've been recognized in this way."



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 **September 1, 2021 and February 28, 2022.**

Transformational (\$1,000,000+)

- Estate of Evemarie C. Gilfillan
- Jay and Linda Grunin Foundation
- Ms. Joan Rechnitz

Visionary Society (\$500,000+)

- Mr. and Mrs. Mark Montenero
- PSE&G 10th Annual Vendor Golf Outing

Benefactor Society (\$250,000+)

- Louise Washington Charitable Remainder UniTrust
- PSEG Foundation

Leadership Society (\$100,000+)

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- Standish Foundation
- The Summit Foundation
- Mr. Nicholas Trovato
- Mr. and Mrs. Frank E. Walsh, Jr.



KIDS CAN BECAUSE YOU CARE



SUPPORT THE CAMPAIGN TODAY AT WWW.GIVE2CSH.ORG



scan to give now

Awariness Isn't Enough. It's All About Acceptance.

Tommy Marcketta is passionate about moving past autism awareness and promoting **autism acceptance**. Tommy was diagnosed with autism spectrum disorder (ASD) when he was seven-years-old, which is later than usual for children living with ASD. Although his mother, Elizabeth, sought help from a specialist for three years, Tommy was never given a proper diagnosis. Elizabeth knew that her son was exhibiting behaviors typical of children on the autism spectrum and she was not about to let him slip through the cracks.

Just before Tommy's eighth birthday, Elizabeth brought him to Children's Specialized Hospital (CSH) for an evaluation with developmental pediatrician, Dr. Tara Matthews. Dr. Matthews delivered the news that Elizabeth was ready to hear—that Tommy did indeed have ASD. When Tommy was finally given his diagnosis he cried—but not because it made him upset. In fact it was just the opposite, he was relieved to know that there were other people in the world that felt like he did—he was relieved to know that he was not alone.

That moment was a turning point for Tommy. He now understood why he experiences things differently from others. There was now a logical reason for why he struggles to make eye contact with people he doesn't know and why he is so sensitive to sound and touch. Knowing that he was living with ASD gave Tommy a brand new outlook



on life. And Elizabeth was now able to get him the care he needed so he would have the opportunity to reach his full potential.

As Tommy learned more about ASD, he felt that the public at large really didn't understand what it meant to be "autistic." To him, the way autism was being discussed in general terms did not truly represent the way he felt or experienced things. That's when Tommy decided that he was going to help others understand ASD better and do everything he could to promote acceptance instead of simply awareness. "Autism isn't just a disease people need to be aware of," said Tommy. "People need to accept that there are autistic people all around them. Instead of expecting them to conform to the typical person's idea of how a person should speak and act, we need to allow them to be authentic and who they are. That may mean that typical people have to be OK with feeling slightly uncomfortable."

Tommy, now in eighth grade, attends mainstream classes and a number of gifted classes at school. He excels in science and actively competes on the

“

In our house, we don't spend time being angry when others are mean or unwilling to accept Tommy's differences... I feel sorry for people who can't look past his diagnosis and get to know this kind and incredible kid.

”

— ELIZABETH MARCKETTA —
Tommy's Mom

Special Olympics swim team. But because he experiences the world differently, Tommy has also experienced bullying in school. He doesn't let it get him down, though. From his perspective, the bullying is a result of a lack of understanding and a fear of people who are different. Last month, Tommy heard a few of his classmates using the word autism as an insult. Instead of getting angry or sad about it, he wrote a letter to the Vice Principal at his school, explained the situation and asked for a meeting so they could work together on a plan to educate the student body about what it really means to have ASD. Tommy and his Vice Principal came up with many ideas and fun ways to share facts about ASD to promote understanding and acceptance in school. Tommy knows that the message won't reach every student, but he hopes that his efforts, no matter how small, will help create a more inclusive world.

Creating a culture of acceptance is so important to Tommy and his family because it moves beyond awareness and allows Tommy to be who he is. Elizabeth is so proud of Tommy's commitment to being a proactive proponent for inclusion and acceptance. "In our house, we don't spend time being angry when others are mean or unwilling to accept Tommy's differences," she said. "I feel sorry for people who can't look past his diagnosis and get to know this kind and incredible kid."

Tommy wants the world to know that having ASD and living in a world designed for neurotypical people is not always easy. According to Tommy, people living with ASD think

differently, can have trouble communicating, don't always recognize or react properly to social cues, and need extra support. But most importantly, people living with ASD are looking for acceptance—just like everyone else. Tommy doesn't want to have to try to blend into the "norms" of the world, he just wants to be able to be himself wherever he goes—and be accepted.

Last year the Autism Society of America began the push to change Autism Awareness Month to Autism Acceptance Month and Tommy and his family couldn't have been happier to hear this news. While awareness is great, a lack of acceptance is what often creates barriers for people living with ASD.

CSH, the largest regional provider of autism services, is dedicated to improving the lives of children and adolescents with ASD. CSH is at the forefront of research for the treatment and diagnosis of autism, conducting various clinical studies focused on improving diagnosis, treatment plans, and a successful transition into adulthood.

Through a collaboration with Kessler Foundation, partially funded by CSH Foundation, CSH is advancing the idea of teaching children "what is right" about them instead of what is "wrong." The Strength Identification and Expression in Young Adults study evaluates how young adults with and without autism identify and express their personal identities. It is important research like this that will drive self-acceptance for autistic children and help more kids, like Tommy, teach others to accept others' differences. ■

Tommy wants to be able to be himself wherever he goes and be accepted.



COLBIE IS CAPTIVATING HEARTS ACROSS NEW JERSEY

Meet Our 2022 Children's Miracle Network Hospitals New Jersey Champion

Colbie Durborow and her twin brother, Bennett, were micropreemies born at just 23 weeks. Micropreemies are the most premature babies of all and are at risk for a number of health conditions—some of which will impact them for their entire lives. Colbie weighed just one pound two ounces at birth, with Bennett weighing just two ounces more. Both babies were ushered into the Neonatal Intensive Care Unit (NICU) where sadly, Bennett passed away just two days later.

All at once, new parents, Amanda and Colin, were dealing with the unexpected premature birth of their twins, the loss of their newborn son, and the uncertainty of their tiny daughter's future. For the next 153 days,

Colbie was in the fight of her life. Her mom, Amanda, recounts, "She had breathing tubes in her lungs, down her throat, beeps and buzzers and everything you'd never imagine your baby wearing."

Two weeks later, Colbie experienced a bilateral brain bleed and began to develop hydrocephalus, the collection of cerebrospinal fluid that puts pressure on the brain and can cause brain damage. At just eight-weeks-old, Colbie underwent the first of seven major surgeries that included six brain surgeries and one eye surgery. She had a Ventriculoperitoneal Programmable Shunt placed to drain the fluid from her brain.

Miraculously, Colbie continued to get stronger and after 153 days in the NICU



she was able to go home for the first time. Her parents were uncertain what her future would hold but were determined to give her every opportunity to reach her full potential. Colbie grew stronger every day but Amanda noticed that her progress was plateauing and made an appointment with a physiatrist at Children's Specialized Hospital. It was then that Colbie was diagnosed with Cerebral Palsy (CP) and began therapy to strengthen her legs and work on her mobility.

Now four-years-old, Colbie is well-known at CSH because of her outgoing, infectious personality that naturally inspires everyone around her. Her strength, resilience, and fighting spirit has earned her the title of 2022 Children's Miracle Network Hospitals (CMNH) New Jersey Champion. As the local CMNH Champion, you may see a lot of Colbie this year as she makes appearances at some of our CMNH partner locations, stars in videos and advertisements, and serves as an ambassador for CSH and CMNH. Colbie and her parents will spend the year advocating for the charitable needs of CSH and children's hospitals across North America. ■

**COLBIE'S PARENTS
TELL THEIR STORY**

Scan this code to view the video.





TOGETHER, WE ARE MAKING MIRACLES

CMNH WELCOMES 3 NEW NATIONAL PARTNERS

Your local Children's Miracle Network Hospitals team would like to give a warm welcome to three new national partners! Throughout the year, you now have the opportunity to give at the register to support Children's Specialized Hospital at their participating locations.

We are thrilled to have them as part of the CMNH family!

ANTHROPOLOGIE

Anthropologie had their first campaign for CMNH during the 2021 holiday season and matched customer donations up to \$100,000! We can't wait to see what's in store for 2022!



Bob's Discount Furniture ran their first campaign in the first quarter of 2022. If you're looking to upgrade your living room furniture, make sure Bob's is your first stop!



JOANN is supporting CSH, and local CMNH hospitals around the country through October! Make a donation at checkout to support local kids and their families at CSH.



SAVE THE DATE



Stop into your local Costco during the month of May to #changekidshealth at Children's Specialized Hospital! Last year, you helped our friends at Costco raise \$705,105—100% of which benefits our patients. **Thank you, Costco!**



Give on the go with Wawa! Between April 11th and May 30th, make a donation to CSH when you shop at your local Wawa. Last year, you helped our friends at Wawa raise over \$100,000 for CSH! We are so excited for this year—**thank you, Wawa!**



From June 13th through July 10th, you can support CSH at your local Walmart or Sam's Club! Whether you're stocking up on summer décor, filling your fridge with fresh groceries, or buying the newest tech for your home, **you can make a donation to support local kids at checkout!**



This summer, beat the heat and celebrate **Miracle Treat Day** at your local Dairy Queen! On July 28th, Miracle Treat Day, \$1 or more from every BLIZZARD TREAT sold at participating locations will be donated to CSH! **It's sweet to give back with our friends at DQ!**



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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

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