

Children's Connection

For the Friends of Children's Specialized Hospital Foundation



Fall Issue 2019



Conner Drummond:
Sharing His Story to
Make a Difference
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Foundation President's Message

Dear Friends,

Welcome to Fall,

I am one of those people who love the change in temperature, the feel of cool autumn air and just a touch of frost on the ground. I know this time of year puts us just a few weeks from Thanksgiving and working here at Children's Specialized, there is a deep sense of gratitude in all we do.

We are grateful to all the families who entrust their children to our clinical experts and we are grateful for the volunteer leadership that guides us in their roles as trustees. We are grateful to work in an organization where we can see the impact of our efforts every single day. And of course we are grateful to you. I have met so many wonderful, kind, patient and generous friends over time, people who have a sincere desire to help children and their families. How could we not be grateful and appreciative?

In this issue we share some of the stories and photographs of people who through their own spirit of generosity have touched the lives of our patients, their families and our staff.

From all of us here, we wish you the best this holiday season has to offer, time with those you love, good health and wonderful memories.

Best Wishes,



Philip Salerno III

Foundation President and Chief Development Officer



“There is a deep sense of gratitude in all we do.”

Philip Salerno III

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Children's Specialized Hospital Foundation



Exciting News from Children’s Specialized Hospital’s Center for Discovery, Innovation and Development (CDID) for Patients Struggling with Executive Dysfunction



Children’s Specialized Hospital’s Center for Discovery, Innovation and Development (CDID) has signed an agreement with ATENTIV, LLC, a specialty service provider remediating executive dysfunction without medication. The collaboration includes co-development of an integrated behavioral and primary care operating system based upon best clinical practices for the delivery of ATENTIVmynd™ by primary care clinicians.

ATENTIVmynd™, a clinically validated therapy shown to remediate the underlying causes of executive dysfunction, is a software-based therapy engineered to naturally activate and generate physiological changes in the neurological pathways that enable human functioning. The therapeutic application continuously monitors the subject’s attention level through an avatar in an adventure video game. A closed-loop system dynamically manages a therapeutic curriculum through a series of video adventures that: identify and target specific dysfunctional executive skills; trains and measures attention state and executive skills development; and enables the transfer of improved executive skills to home and school.



Children’s Specialized Hospital sees over 10,000 children with executive dysfunction annually. Executive function involves the organization and regulation of behavior to accomplish goals. Executive dysfunction impairs goal-oriented behavior, which includes underlying skills of attention, inhibition, memory, cognitive flexibility, reasoning, critical thinking and decision making. Children with Attention Deficit Hyperactivity Disorder (ADHD) struggle with executive skills dysfunction, which frequently result in poor academic performance and challenging home behavior.

“We are thrilled to collaborate with ATENTIV, LLC on this innovative program. Strategic partnerships like this, that focus on improving patient outcomes, ensure we are that much closer to fulfilling our vision of a world where all children can reach their full potential.”

Warren E. Moore, FACHE, Senior Vice President, Pediatric Services for RWJBarnabas Health President & Chief Executive Officer of Children’s Specialized Hospital

“Provider and payers are limited in their ability to provide patients with accessible, affordable and sustainable therapeutics to address executive dysfunction,” says Eric B. Gordon, Founder and CEO of ATENTIV, LLC. “The joint collaboration between ATENTIV and CDID signifies an important step forward in the integration of behavioral health into primary care, which could lead to dramatic improvements in access, quality and outcomes within primary care, with significant short and long-term cost savings for the consumer, payer and provider.”



Teeing Up for Inpatient Programs

At the 8th Annual PSE&G-Electric Transmission & Distribution/ Vendor Golf Outing, over 250 golfers and 67 sponsors united for an exciting day of golf on the nearly 1,000 acres of spectacular countryside at Fiddler’s Elbow Country Club in Bedminster, NJ. The event raised a record-breaking \$425,000 for inpatient programs at PSE&G Children’s Specialized Hospital in New Brunswick, NJ. To date, PSE&G and its vendor community have raised more than \$2.3 million for Children’s Specialized Hospital through this annual outing.

The Inpatient program at PSE&G Children’s Specialized Hospital provides a broad range of medical and rehabilitative care with a comprehensive approach for children with complex healthcare needs. **“These critical funds help our doctors, nurses and therapists pursue ongoing research to ensure that our Hospital’s inpatient programs remain at the forefront of treatment methods, with the most innovative equipment and therapies,”** says Philip Salerno III, Children’s Specialized Hospital Foundation President and Chief Development Officer.

Guest speakers, Peter and Abby Hansen with their daughter Leah, shared Leah’s miraculous story of rehabilitation and recovery while Leah was an inpatient at Children’s Specialized Hospital. After suffering a severe stroke, Leah arrived at Children’s Specialized a quadriplegic. After many months of



Pictured at the 8th Annual PSE&G-Electric Transmission & Distribution/ Vendor Golf Outing, Kim Hanemann, Senior Vice President PSE&G Electric Transmission and Distribution and Children’s Specialized Hospital Board Trustee, with the Hansen family and Warren E. Moore, FACHE, President and CEO, Children’s Specialized Hospital and Senior Vice President, Pediatric Services, RWJBarnabas Health.

intense therapies, Leah is walking and talking. The Hansens are grateful to have benefitted from the programs this event is helping to finance, “Leah is back in school and thriving because of the amazing care she received at PSE&G Children’s Specialized Hospital,” says Peter Hansen.

Join Us at the
2019 Jingle Bell Run 5K



December 8, 2019
The Mills at Jersey Gardens

Team Costume Contest * Awards * Food * Fun Run with Santa

A fundraiser to benefit
Children’s Specialized Hospital



Come out and enjoy a family-friendly fundraising day with the Elizabeth PBA #4, Children’s Specialized Hospital, Jersey Gardens and Santa at The Jingle Bell Run 5K!

Participants of ALL ages welcome!

- * All participants will receive special Jingle Bell 5K gear, swag bag, and jingle bells for shoe laces.
- * Awards ceremony and gift cards awarded to the 1st (\$250), 2nd (\$100), & 3rd (\$50) Place male and female finishers!
- * Team COSTUME Contest sponsored by the Mills at Jersey Gardens.
- * Complimentary pancake breakfast for registered runners and walkers courtesy of IHOP.
- * USATF Certified course.

Friends and Family are welcome to participate in breakfast when they give a donation to Children’s Specialized Hospital.



Children's Specialized Hospital Foundation 32nd Annual Umbrella Gala: Setting the Stage for a Brighter Tomorrow

Children's Specialized Hospital Foundation celebrated the 32nd Annual Umbrella Gala on Friday, October 18, 2019 at Gotham Hall in New York City. **Raising over \$325,000**, the proceeds from this year's Umbrella Gala benefit Children's Specialized Hospital's Neonatal Abstinence Syndrome (NAS) Program. The evening celebrated two corporate honorees, Johnson & Johnson and PNC Wealth Management, both providing leadership and guidance to encourage innovative growth and opening new doors to partnerships, helping to create new opportunities for patients of Children's Specialized Hospital.

PNC Wealth Management has been a generous supporter of the hospital's Early Intervention Program through their foundation and has helped to access hundreds of thousands of dollars from other foundations. Stella Matteace-Esposito, SVP and Senior Relationship Strategist/Manager at PNC Wealth Management and Children's Specialized Hospital Board Treasurer accepted the honor on behalf of PNC Wealth Management.



John Crisan, Chief Privacy Officer at Johnson & Johnson and Children's Specialized Hospital Foundation Board Chair accepted the award on Johnson & Johnson's behalf. J&J is one of the Foundation's longest standing corporate partners and has provided tremendous support for more than 30 years. From support for the expansion of outpatient therapy

programs to supporting nursing effort, to providing countless volunteers, J&J has been a steady and important corporate partner.



"The Foundation would not be what it is today without the leadership of John Crisan and Stella Matteace-Esposito," said Philip Salerno, III, Children's Specialized Hospital Foundation President and Chief Development Officer. "I'm thrilled to honor them and their corporate stewardship at this beautiful evening raising necessary funds for our children."

"It was a special evening celebrating all the stars that support Children's Specialized Hospital," said Beth Anne Dobosh, Director of Corporate and Foundation Partnerships at Children's Specialized Hospital. "We are so grateful to our amazing Gala Committee, led by co-chairs Don and Libby Pearl, for helping to make this event possible and to Candi Symington for sharing her moving story with our guests."





Conner Drummond and his family: Sharing their story to help others with complex health challenges

M **Meet Conner Drummond:** He is a happy, energetic nine-year old who loves playing with his older brother, CJ, and values his independence. This young boy with a warm smile and beautiful eyes has come a long way since he was born in 2010. His mom, Katiane, tells the traumatic story of his premature delivery at 25 weeks. At birth, Conner suffered a grade 4 brain bleed leading to a diagnosis of cerebral palsy, vision loss and a seizure disorder. He stayed in the neonatal intensive care unit for 137 days. When the Drummonds were finally able to bring their baby boy home, he still had a feeding tube, heart monitor and oxygen tank. Katiane and Clinton were scared and overwhelmed when they first arrived home with Conner, but they were strong and determined to give him the best possible care.

Almost immediately, Conner began receiving early intervention program (EIP) services, funded in part by the Department of Health, coordinated by Children’s Specialized Hospital. This program provides early identification, evaluation and intervention for children up to three years of age who have a documented condition that impairs or has a high predictability of impairing normal development and/or who have measurable developmental delays. Services provided are speech, occupational and physical therapies, nursing, social work/family training and developmental intervention (teaching). All of the services are provided in the child’s home or in a community

setting where he or she is comfortable. In Conner’s case, in addition to working with a teacher for the blind, he received occupational and physical therapies.

When Conner turned three, he began outpatient physical therapy at Children’s Specialized Hospital’s Plum Street location with Lauren Castagna. “Conner has an incredible strength and willingness to achieve anything he wants,” says Lauren. “With the support of his family and dedication to his therapies, he has made great strides in his physical abilities. He also has the best sense of humor and contagious laugh, making every session with him a joy!”

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Lauren Castagna, Conner’s Physical Therapist



“All of Conner’s therapists, doctors and nurses always make sure I am included in every plan to benefit Conner’s development and meet his needs and, equally important, they taught me strategies to advocate on Conner’s behalf.”

Katiane, Conner’s Mom



Katiane appreciates always being involved in every aspect of planning Conner’s care, “All of Conner’s therapists, doctors and nurses always make sure I am included in every plan to benefit Conner’s development and meet his needs and, equally important, they taught me strategies to advocate on Conner’s behalf.”

In fact, this past summer the Drummonds travelled to Washington, DC to take part in Speak Now for Kids Family Advocacy Day and urge Members of Congress to improve healthcare for children with complex medical conditions by safeguarding Medicaid. “Though our story is not unique in that our child is differently abled, Conner’s life shows the broad spectrum of difficulties that families face,” says Katiane. “Every child is different and each has a unique story, but too often children require extensive medical intervention that leaves many families like ours in financial distress. Our goal is to continue to work towards the accessibility of quality medical services for all children.”

Katiane also joined the Family Advisory Council at Children’s Specialized Hospital. The council is a group of families and staff working together to promote the hospital’s mission of family-

centered care. The Family-Centered Care team provides the focus and unique family perspective required to build awareness, educate, engage, and fully integrate Patient- and Family-Centered Care principles into the healthcare policies, practices and services across the hospital. “I am so proud of all that Conner has accomplished and grateful to everyone at Children’s Specialized who has invested their time in him,” said Katiane. “I joined the council hoping that by sharing our story and experiences, we can make a positive impact for other families in similar circumstances.”

Conner is in school now and he continues outpatient therapies in Mountainside. Always seeking more independence, Conner has learned to crawl and loves the freedom that affords him. His feeding tube was removed when he turned five and with the help of occupational therapy he learned to spoon feed himself. All amazing milestones that he’s crushing! With the help of his therapists and the love and support of his family, Conner is making progress every day. And we can’t forget to mention that he loves to dance, dance, dance!

Tune-in to hear Conner’s Story on the Making Miracles Radiothon



**December 4th & 5th
92.7 WOBM
6am-6pm daily**



Conner, his parents Katiane and Clinton and brother CJ at the Capitol Building for Speak Now for Kids Advocacy Day. The Drummonds and Warren E. Moore, FACHE, President & CEO, Children’s Specialized Hospital and Senior Vice President, Pediatric Services, RWJBarnabas Health, met with Members of Congress to urge them to improve healthcare for children with complex medical conditions by safeguarding Medicaid and reauthorizing the Children’s Hospitals Graduate Medical Education (CHGME) program.



New Program for Teens Living with Chronic Illness, *Cook Healthy!*

Thanks to a generous \$25,000 grant from ShopRite, the Chronic Illness Management Program at PSE&G Children’s Specialized Hospital in New Brunswick has developed a new program, *Cook Healthy!*, which is designed to enhance health outcomes for teenagers living with chronic illnesses.

As part of the grant, *Cook Healthy!* draws upon the nutritional expertise of the ShopRite of Somerset’s in-store dietitian Aliz Holzmann, RD, to provide healthy diet and wellness education to patients and families, helping them better manage their chronic illnesses and maximize quality of life.

During the lessons at ShopRite in Somerset, which take place at the supermarket, and are led by Holzmann, children and families are provided with age appropriate education specific to their chronic illness and dietary needs. A primary objective of the program is to promote the use of fresh and affordable ingredients as well as to learn about local and/or seasonal foods to improve the health of the participants and their families.



Patients of Children’s Specialized Hospital’s Chronic Illness Management Program learn healthy cooking skills at ShopRite in Somerset as a part of the newly-introduced Cook Healthy! program. The expectation is that each patient will be significantly more independent at managing his or her medical condition after participating in the Cook Healthy! program.

“Cook Healthy! provides a fun, hands-on education that leaves a lasting real-life impact far beyond the ShopRite walls,” indicated Ayana Hamilton, Patient Care Navigator, Chronic Illness Management Program at Children’s Specialized Hospital. **“I have seen patients facing chronic illness become significantly more independent at managing his or her medical needs almost immediately thanks to this program.”**

Research has shown that when youth are involved in preparing food, they are more likely to eat nutrient-rich foods, with higher intakes of fruits and vegetables and key nutrients, and lower intakes of fat. The program also provides a fun activity for children and their families to get excited about and enjoy. The expectation is that each patient will be significantly more independent at managing his or her medical condition after participating in the program.

“ShopRite is pleased to have the opportunity to partner with such an important and esteemed organization as Children’s Specialized Hospital,” says Perry Blatt, Director of Marketing and Business Development for Village Super Market, Inc., which owns and operates several ShopRite supermarkets. “We’re proud to assist the community by helping to underwrite programs such as this.”



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Perry Blatt
Director of Marketing and Business Development for Village Super Market, Inc.



Donor Spotlight: **Meet Pinky Shah**



Pinky Shah recalls the long drives to Children’s Specialized Hospital (CSH) in Mountainside from her childhood. Her family made the trip from their home in Hudson County several times a week. Her older brother Mital, born with Cerebral Palsy, received treatment multiple days each week at CSH. Pinky describes Mital as a very giving person and credits him with teaching her how to help others. Sadly, Mital passed away in 2005 at 32 years of age. “Even in his final years which included months of hospitalization and going through more pain and emotional stress than I can ever imagine, he still was always thinking of others. When I visited after work, the first thing he asked me is if I ate.”

After Mital passed, Pinky and her family wanted to do something to honor him. Hoping to help others with health challenges, they saw an ad for the CSH Walk n’ Roll and decided to participate in honor of Mital. They encouraged family and friends to join and were overwhelmed by the support. A few years later, Pinky’s niece was born. She too, had Cerebral Palsy and became a patient at CSH. Even more family and friends came out in support. Their team, now named J&M High Rollers grew larger. “Now it has become a family tradition—a great opportunity to spend time together while giving.”

Pinky, a successful mortgage lender, still desired to do more. “I wanted to find a way to build giving into my business.” She began by collecting items requested by the hospital from her clients and business partners a few times a year. Whether toiletries or scrapbooking items, she devotedly gathered whatever was needed. Still, she wanted to do more and decided to make a donation in honor of each and every client for whom she closed a mortgage. “This makes giving a piece of cake! I am so happy that we donate to CSH every month and have the privilege of helping so many children and families. And, it is an incredible legacy for Mital.”

A SPECIAL THANK YOU TO OUR DONORS

Children’s Specialized Hospital Foundation acknowledges the generous support of its donors. Gifts to Children’s Specialized Hospital Foundation ensure that our patients receive the best possible care from the most skilled doctors and therapists.

We would like to recognize the following major donations from June 1, 2019 to August 31, 2019:

Visionary Society Donors (\$500,000 +)

Kohl’s Department Stores, Inc.

Humanitarian Society Donors (\$50,000 +)

The Healthcare Foundation of New Jersey

Founder Society Donors (\$25,000 +)

American Pile and Foundation LLC

Anonymous

Burns & McDonnell Engineering Co.

Ferreira Construction Co., Inc.

Henkels & McCoy, Inc.

Wakefern Food Corporation

Cornerstone Society Donors (\$10,000 +)

Angelo Fiorito Trust

Anonymous

Robert Benzinger

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Goldman Sachs Gives

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Johnson & Johnson Consumer Products Company

Kean University Greek Senate

OceanFirst Foundation

Playball for Miracles

PNC Financial Services Group

Sargent & Lundy, LLC

The Blackstone Charitable Foundation

Vericon Construction Company

A Great Day of Fun, Sunshine and Support at the 13th Annual Walk n' Roll

On September 15, Children's Specialized Hospital Foundation's 13th annual Walk n' Roll brought together over 2,000 people who raised over \$200,000 to help children with special healthcare needs. Every step and every roll at this year's event will specifically support the programs and services at the hospital's New Brunswick site, helping make it possible for all children to receive the specialized care needed to learn to walk, talk, eat and breathe independently - again, or for the first time.



Top fundraising team, Team Ariana, raised over \$14,000! Luciana McGuire, Ariana's mom and a staff member of Children's Specialized Hospital's Family Faculty, has been an avid walker since 2011.

"Every year Walk n' Roll is an event we really look forward to," says Luciana. **"It's inspiring to see how the event has grown over the years and to be the top fundraising team this year is exciting! Walk n' Roll serves as a reminder as to how Children's Specialized Hospital is making a difference in the lives of so many."**



Conner's family and friends joined the fun at the Walk n' Roll on September 15th in Johnson Park.

"We had a perfect day for the Walk n' Roll this year! It was amazing to see so many children and families gathered together to support our hospital," said Philip Salerno, III, President and Chief Development Officer of Children's Specialized Hospital Foundation. "We're grateful to our Walk n' Roll committee co-chairs Jennifer Weill and Ananda Kanapathy and presenting sponsor PSE&G, their generous support helps make this special day possible."



It was an inspirational day highlighting the dedication so many families feel to the organization that has given them so much. For more information or to donate, visit www.childrens-specialized.org/walk



Leave us a little behind...



It's easy. Your legacy can begin today.

That transformational gift you want to make doesn't have to wait – you can create a better future for our children today with a gift that costs nothing during your lifetime.

A planned gift to Children's Specialized Hospital through your will or trust (a "bequest") makes it possible.

- You can make a generous commitment to their future right away.
- It will not reduce your savings or your cash flow.
- It is revocable, so you can make changes if you choose.

Making a bequest is easy – you don't have to rewrite your will.

You can leave your mark on the future. *Start being remembered today.*

For more information, please contact Elena Herskowitz
at eherskowitz@childrens-specialized.org or call 908-301-5462.





Welcome Life Time, A New Children’s Miracle Network Hospitals Partner

We are proud to welcome Life Time as a new Children’s Miracle Network Hospitals partner. On October 12th, 32 Life Time destinations across the country hosted the inaugural “Crushin’ It for the Kids” charity workout event. Four of those locations – Bridgewater, Florham Park, Berkeley Heights and Bergen benefitted us at Children’s Specialized Hospital. Participants partnered with family and friends to raise funds for Children’s Specialized Hospital and the Life Time Foundation while pushing themselves and their bodies to new levels during a challenging Alpha or GTX workout.

The energy felt on October 12th shed light on Life Time’s commitment to championing a happy and healthy life for its members, as well as its members’ unequivocal passion for making a difference. The more than \$100,000 raised across the country through “Crushin’ It for the Kids” will impact the smallest, sickest and most vulnerable members of the communities Life Time services for years to come. **Locally, we raised over \$22,000, with our Bridgewater location being the top fundraising location in the country!**

Thank you, Life Time, Life Time members and Crushin’ It for the Kids participants!



SAVE THE DATE

November 29 - December 25, 2019*
Ace Hardware’s Holiday Round Up

December 4 - December 5, 2019
WOBM Radiothon

December 3 - December 24, 2019
Nordstrom Register and Gift Tag Campaign

January 1 - February 25, 2020
IHOP Balloon Campaign

February 25, 2020
IHOP National Pancake Day

March 15 - March 17, 2020
Speedway St. Patrick’s Campaign

March 19, 2020
Dairy Queen Free Cone Day

** Participating locations only*

For more information on these events, please contact Nicole Hudson at nhudson@childrens-specialized.org



RE/MAX: Helping to Make Miracles Happen

RE/MAX real estate agents help Children's Miracle Network Hospitals support millions of kids each year, fundraising nearly \$160 million since 1992. Locally, there are wonderful offices in New Jersey who continuously show their support for Children's Specialized Hospital. Through the Miracle Home Program, RE/MAX associates can choose to make a donation to their local Children's Miracle Network Hospital after each closed real estate transaction! Local RE/MAX offices often host events throughout the year as well to raise money for our kids such as golf outings, casino nights, photos with Santa and more!

Thank you, RE/MAX, for all the love and support of our hospital - and truly making kids live better lives.



Children's Specialized Hospital Foundation Board Member Vincent Baricaua leads RE/MAX Our Town to be the 3rd highest fundraising RE/MAX office in the country for Children's Miracle Network Hospitals. His signature event, "Raising the Stakes for a Miracle" took place October 19th.



RE/MAX Diamond's Top Golf fundraiser.



RE/MAX Country Walking Miles of Smiles with Luis at Walk n' Roll.



RE/MAX 100 at their Great Gatsby Gala.



Children's Specialized Hospital's Board Member, Dana Mauro, celebrates RE/MAX LTD's 10th Annual Golf Outing with fellow committee members.



Photo Gallery



MSCP Certified Public Accountants and Advisors raised \$10,000 from their annual golf outing and anniversary dinner.



Many thanks to NY Giant Oshane Ximines and PSE&G for the special visit with our patients and their families in New Brunswick.



New York Red Bulls player, Tom Barlow, and CMN Hospitals partner, Speedway, stopped by Children's Specialized Hospital in Mountainside to deliver a Starlight Fun Center.



Kohl's Associates in Watchung, NJ volunteered their time and craft skills to make amazing Super Mario Kart-themed decorations for the Activity Connection's Camp Chatterbox.



Thanks to the Marisa Tufaro Foundation, patients and families were treated to a wonderful Jersey Shore boardwalk-themed celebration in July. The evening included carnival games, live music, prizes, arts and crafts, a DJ and summer food favorites in honor of Marisa Tufaro's 16th birthday.



Give a gift you can't buy in the store: *Hope.*

Make the holidays — and their future — brighter with a wish list gift.

With the holidays around the corner, you can give a gift that will impact a lifetime. Grant a holiday wish that will make a world of difference through a tax-deductible donation to Children's Specialized Hospital Foundation.

Your donation will help a child with special health needs and make a difference long after the holidays are over.

 **\$25 Gift of Creativity:** Creative supplies for children's art therapy

 **\$50 Gift of Play:** Toys, games and activities to help with rehabilitation

 **\$100 Gift of Therapy Supplies:** Essential supplies for physical therapy

 **\$150 Gift of Recreation:** Activities like camps and events for teenage patients

 **\$250 Gift of Mobility:** Mobility aids to help children move independently

 **\$500 Gift of Technology:** Tech devices that help children achieve their goals

 **\$1,000 Gift of Rehabilitation:** Tools that assist with recovery, like therapy tables

 **\$5,000 Gift of Recovery:** Financial help for un-insured or under-insured patients in need

Make a meaningful gift this holiday season. To learn more or grant a wish with one click, go to www.childrens-specialized.org/wishlist today.



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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 developmental and behavioral issues like autism and mental health. Working with parents and families, award-winning doctors, researchers and pediatric specialists, Children's Specialized Hospital depends on the generosity of donors to discover new innovative ways to help more children overcome their health challenges. All donations go directly to help pioneer new specialized children's care and serve more children in need.



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To learn more about
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