



Children's National

# Believe

WINTER 2023

**New Hope  
for Kids With  
Brain Tumors**

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**A Former Patient  
Becomes a Nurse  
at Children's National**

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**Light Up Dr. Bear  
This Holiday Season**

"I had brain tumor surgery,  
when I was 2. I used to be  
scared, but not anymore."

— Bennett

**Get to Know  
President & CEO  
Michelle Riley-Brown**



# Letter From the Foundation President



“Every gift Children’s National receives makes a world of difference for the sick and injured patients who rely on us.”

— DeAnn Aston Marshall, M.H.A.

It was an exciting year of new beginnings at Children’s National Hospital.

We welcomed President and CEO Michelle Riley-Brown, MHA, FACHE, who is leading the more than 150-year-old pediatric institution with passion and purpose. I had the pleasure of interviewing her for this issue of Believe. I hope you enjoy learning all about Michelle and her vision for the future.

Children’s National received two transformational investments that offer new hope and the promise of better outcomes for patients.

One, from an anonymous family, ushers in a new era of research and care for children with hard-to-treat brain tumors and supports their life-time journeys. This significant funding will help us deliver more success stories like Bennett’s.

Another extraordinary gift from our longtime partner, the United Arab Emirates, will create healthier futures for kids in our community and around the world.

Every gift Children’s National receives makes a world of difference for the sick and injured patients who rely on us. Your generous support, including for the Fund for Every Child, advances our work across the entire hospital system. Thank you for helping us step up for families who need us when it matters most.

I wish you and your family the happiest of holidays and a healthy 2024!

**DeAnn Aston Marshall, M.H.A.**  
President  
Children’s National Hospital Foundation



“When I walk in the hospital and see those balloons in the atrium, I know it’s a special place. I feel safe there.”

— Bennett, Children’s National patient

Brian Rood, M.D., director of clinical neuro-oncology and medical director of our Brain Tumor Institute, checks in with Bennett

# Believe

WINTER 2023

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Children’s National Hospital Foundation works with generous donors to advance the hospital’s mission. Gifts from individuals, corporations, foundations and community organizations fund world-class care and research for kids in the Washington, D.C., region and beyond.



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Cover: Bennett, a Children’s National patient

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**“Having the insider view of a former patient, I put a lot of pressure on myself to be a superstar nurse.”**

— Kyle, Children's National nurse

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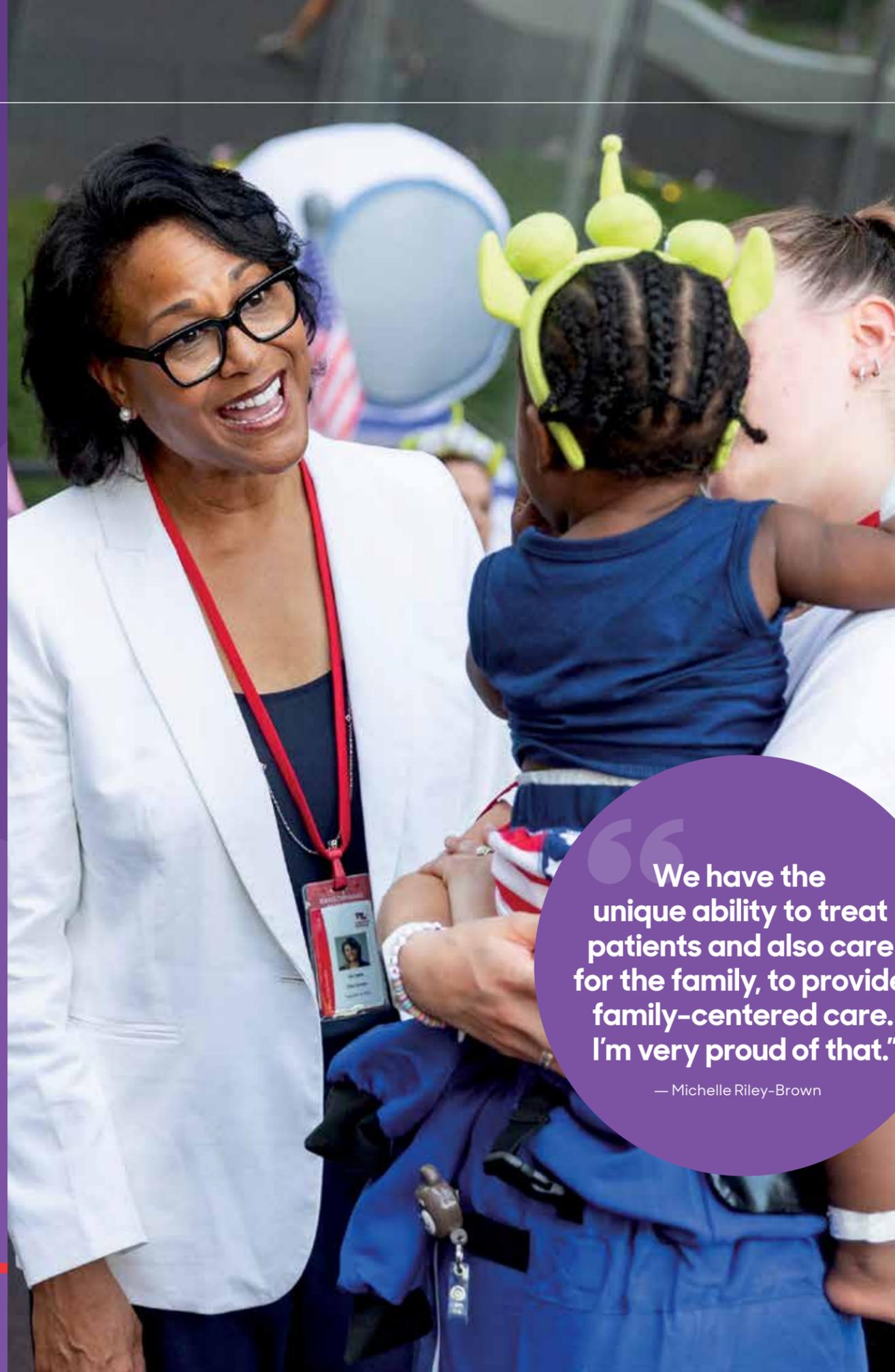
Your donation this holiday season supports our care and research and lights up special hospital mascots to delight patients and their families.

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## LEAD THE WAY

# Get to Know Children's National President & CEO Michelle Riley-Brown



“We have the unique ability to treat patients and also care for the family, to provide family-centered care. I'm very proud of that.”

— Michelle Riley-Brown



Michelle Riley-Brown, MHA, FACHE, and DeAnn Marshall, MHA

Michelle Riley-Brown joined Children's National as chief executive in July, bringing 24 years of pediatric healthcare leadership to her new role. Previously, she was an executive vice president at Texas Children's Hospital at Texas Medical Center in Houston, where she served as president of two hospitals and led construction and staffing of a third. She sat down with Foundation President DeAnn Marshall to talk about her background and goals as she leads Children's National into the future.

**DEANN: Michelle, it's a pleasure to be with you. What inspired your career in pediatric healthcare?**

**MICHELLE:** My father was a general surgeon in New Orleans. As a young child, I saw his passion for the healthcare profession and watched him be the epitome of a servant leader. He wanted to make a difference and strive to create a healthier community. That inspired me. I'm the youngest of five children, and my father had a big influence on all of us. My brother is a physician and medical school president, and my sister is a nurse. My late sister was a hospital administrator. We just are very passionate to follow in his footsteps.

**DEANN: What is your vision for Children's National?**

**MICHELLE:** It's an organization singularly focused on helping children thrive — a hospital and integrated delivery system that not only provides the highest quality care but also the ideal patient experience for every family that walks through our doors. It's an organization that pursues cutting-edge research and novel breakthroughs for pediatric disease.



Michelle with family members at her October welcome dinner



Michelle with Nurse Gieshla Moore, M.S.A., M.S.N-Ed., R.N., in the emergency department



Michelle with leaders in our Cell Enhancement and Technologies for Immunotherapy laboratory

**DEANN:** What have you learned through the years that you're bringing to Children's National?

**MICHELLE:** I've learned as a healthcare leader that you have to remain flexible and adaptable because everything changes every day. You have to continue to learn and develop with your team and the organization.

**DEANN:** What are the biggest challenges you see in pediatric healthcare right now and how philanthropy can help overcome them?

**MICHELLE:** We treat some of the sickest kids with very complex health conditions. That can be very expensive for families. We want all children, regardless of their background, to have access to quality care. Not everyone can afford the quality care that they deserve. Philanthropy can help provide it and really make a difference.

**DEANN:** I agree. What's one thing you'd like our donor community to know about you?

**MICHELLE:** I'm passionate about children's hospitals because we have the unique ability to treat patients and also care for the family, to provide family-centered care. I'm very proud of that. That's what I love about pediatric healthcare. Our philanthropic community can help us develop and deliver that comprehensive healthcare model for the child.

**DEANN:** Does your family have a favorite holiday tradition? If so, how do you plan to celebrate it this year?

**MICHELLE:** I like to slow down during the holidays and spend time with my husband and daughter. We also travel to see my siblings or my mother who's in New Orleans. She's 86 and loves when all of her children come home. I take the holidays as a time to really reflect on the past year with gratitude. I'm trying to extend that to my daughter. She likes to cook. I'm not really as much of a cook, but she's teaching me. We also like to bake together, which is becoming a tradition.

**DEANN:** Wonderful. What has been most meaningful to you during your tenure here so far?

**MICHELLE:** It's been heartwarming, DeAnn, and actually overwhelming how welcoming everyone has been. They've opened their arms and doors to me, and it immediately felt like home. That was validation that I was meant to be here. It's also a reminder of how our donors can help us create that feeling of home for our patients and families with everything they do to support the hospital. It's really important. I'm grateful for the community and all they do for Children's National.

**DEANN:** Michelle, it's going to be really exciting to see what you achieve and what we all do together. Thank you so much.

“Not everyone can afford the quality care that they deserve. Philanthropy can help provide it and really make a difference.”

— Michelle Riley-Brown



Scan to watch highlights from the interview



# BRAIN POWER

*A research and care revolution  
for children with brain tumors*



## The Long Game

It takes a lot of brain power to drive a golf ball down the fairway or sink a putt for a birdie. Mental focus, coordination and strategy all come into play. Bennett, 18, takes joy in these challenges. He loves to hit "monster drives" on the links near his home in Washington, D.C. "It takes time to learn how to bend your knees, aim your target and make sure you don't get a bad shot," he says.

Bennett can appreciate the rewards of patience. He has come a long way since doctors discovered a tumor near his brainstem

as a toddler. A medulloblastoma gripped his cerebellum, the brain's coordination hub for movement and balance. Neurosurgery, chemotherapy and radiation left him unable to walk, talk or use his left hand by age 3. The back of his head still bears a scar.

"He had to relearn everything," says his mom, Jen, recalling a recovery journey that continues. These days, Bennett's family celebrates each of his fairway drives. They also cheer when they learn about breakthrough progress in pediatric brain tumor care and research.



Bennett at home with his parents, Jay and Jen



Bennett's sister Emma (right) read him stories during treatment

## Revolution Time

Brain cancer is the deadliest form of childhood cancer. Removing tumors from a developing brain remains both complicated and risky. Conventional treatments can help patients like Bennett survive, yet they often lead to lifelong complications and cognitive impairments. We know we can do more. Today, novel scientific approaches and care advancements – fueled by philanthropy – offer new hope.

In June 2023, Children's National announced a \$96 million investment in rare brain tumor research and care from an anonymous family. The partnership is lifting the field, revolutionizing treatment alongside research partners worldwide and pioneering a new standard of psychosocial care. The investment builds upon an upswell of donations in recent years from an array of generous patient families and partner organizations. It provides a catalyst for additional

philanthropic investments, grants and cross-institutional collaborations – each crucial to the global search for cures. "Today, thanks to our community, we have the chance of a lifetime to transform care," says Roger J. Packer, M.D., who leads the Children's National Brain Tumor Institute.

Pediatric brain tumor science stands at an inflection point for transformation after decades of incremental progress.

Government funding lags behind support for adult efforts. Only about 8 cents of every \$1 for cancer research funding goes

toward pediatrics, according to the National Cancer Institute. The pharmaceutical industry favors clinical trials for adults since they represent a larger market and less financial risk.

This slows pediatric progress, despite the urgent unmet needs of patients and their families. It also neglects that children's brain tumors often are unique to each developing brain. Patients with the deadliest tumors – such as diffuse intrinsic pontine gliomas (DIPG) or relapsed medulloblastomas – currently have no effective treatment options.

**“We have the chance to help patients not only survive brain tumors but thrive with fewer lifelong consequences of care. We will seize this moment.”**

— Elizabeth Wells, M.D., M.H.S., Senior Vice President  
Center for Neuroscience and Behavioral Medicine



Dr. Roger J. Packer, who leads the Brain Tumor Institute, examines a patient

## BRAIN TUMOR FACTS



**5,000** children are diagnosed with a brain tumor in the U.S. each year



**2nd** most common type of pediatric cancer after leukemia



**>75%** average survival rate five years after diagnosis but often with neurologic complications



**<5%** current five-year survival rate for certain tumor types such as DIPG

**Only 8 cents of every \$1** for cancer research funding goes toward pediatrics.

— National Cancer Institute

## A Blueprint for Brighter Futures

New philanthropic investments arrive at a moment of tremendous scientific potential. The molecular underpinnings of childhood brain cancer have never been clearer. New technologies are fueling individualized treatments unique to children. Breakthrough approaches promise to cure tumors without the inner and outer scars and toxicity of conventional treatment. These include the use of a child's own immune system cells to eliminate cancer.

Yet, novel child-focused approaches struggle to attract funding. "That's why philanthropy is so critical. It seeds fresh thinking and gives us the freedom to pursue the most promising therapies with greater speed," says Catherine Bollard, M.B.Ch.B., M.D., director of the Children's National Center for Cancer and Immunology Research and interim chief academic officer.



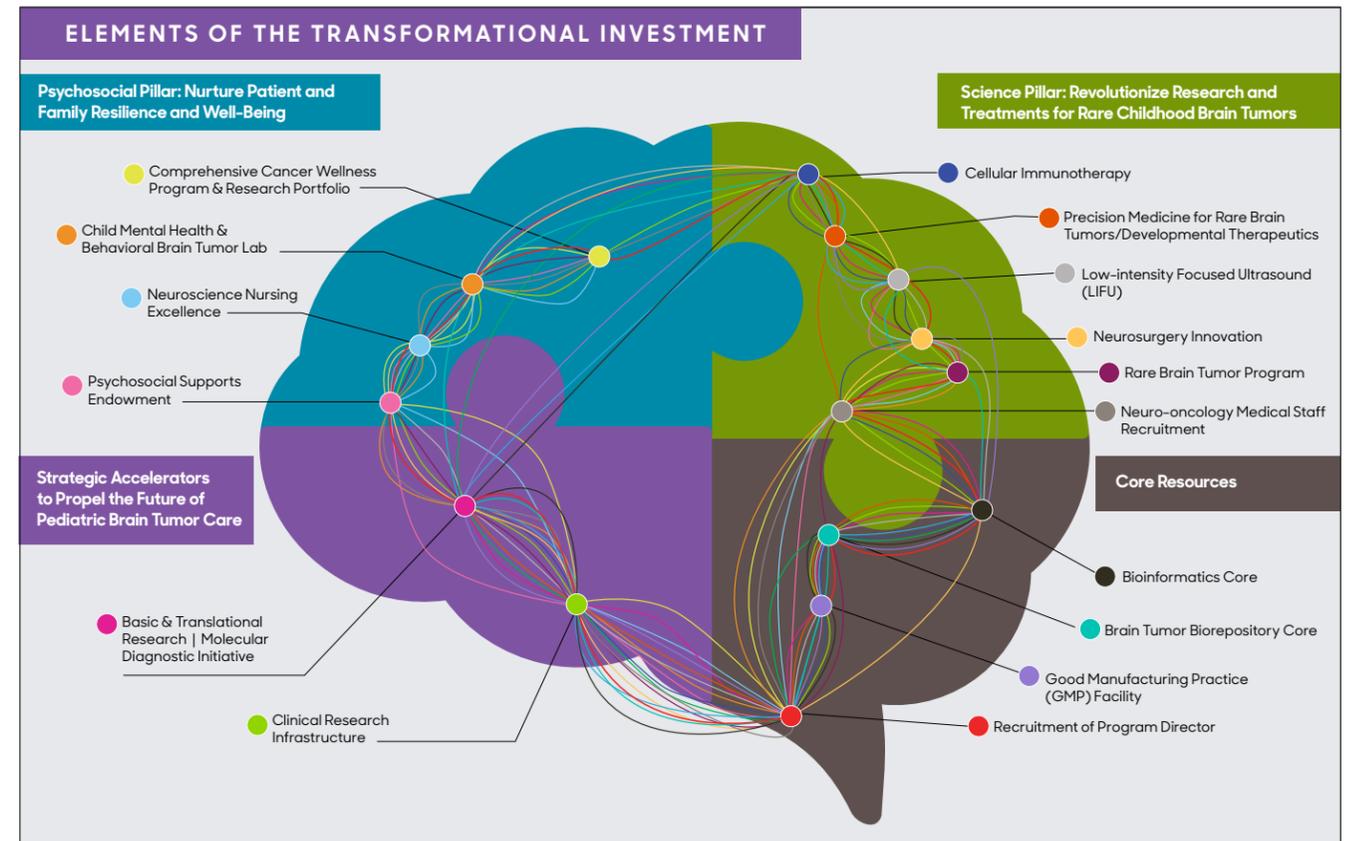
Through world-class brain tumor research and care, we aim to light up more smiles

“Philanthropy is so critical. It seeds fresh thinking and gives us the freedom to pursue the most promising therapies.”

—Dr. Catherine Bollard



Dr. Catherine Bollard leads revolutionary cellular immunotherapy efforts



Children's National is accelerating its work to save and improve lives. The \$96 million investment drives research and clinical innovation in partnership with leading brain tumor programs around the world. It funds two pillars.

The psychosocial pillar will pioneer a new standard of care. It will fuel lifetime health and wellness, mental and behavioral health, neuroscience nursing excellence and a support team that includes child life specialists and music therapists.

The science pillar drives five key priorities:

- Low-intensity focused ultrasound** – eliminate tumors without incision
- Cellular immunotherapy** – treat cancer using the patient's own cells
- Rare tumor research** – offer new hope for children with uncommon cancers
- Neurosurgery innovation** – improve effectiveness and reduce side effects
- Precision medicine & developmental therapeutics** – discover patient-specific treatments

**Breakthrough approaches promise to cure tumors** without the inner and outer scars and toxicity. These include the use of a child's own immune system cells to eliminate cancer.



Declan, with Dr. Roger J. Packer by his side, rings the victory bell after completing chemotherapy

## Beyond the Bell

Cancer treatment is a tough road. We celebrate each ringing of our victory bell, which marks its successful completion. But that happy moment often marks the start of a longer journey. Three out of four oncology patients experience chronic medical conditions or secondary issues.

"The need for evidence-based, longer-term clinical care is immense," says Jeffrey Dome, M.D., senior vice president of our Center for Cancer and Blood Disorders. "The new investment will put more families on the path to better lifetime outcomes."

With this new financial support, a neuropsychologist will screen every brain tumor patient for appropriate and timely interventions. A dedicated neuroscience nurse will ensure seamless care coordination across the continuum of specialists involved in that child's care.

"Children are whole people," says Jennifer Levine, M.D., M.S.W., medical director of our Comprehensive Cancer Wellness Program. "Their success is dependent on addressing all aspects of life. This includes physical therapy, nutritional guidance, long-term cardiac, reproductive health and support for their mental and behavioral health."



Dr. Jennifer Levine joined Children's National in 2023, thanks to new philanthropic investments.

## Fighting for Jace

By Jennifer, Children's National parent

Our son Jace was born healthy and energetic. As a toddler, he wanted to explore everything and found joy everywhere. He would take off, and I'd find him helping his grandfather in the garden or playing fetch with our dog.

When he was 4, he started dragging his left leg and holding his left arm close to his body. A CT scan revealed a brain tumor. Our lives stopped. Jace had DIPG, a terminal diagnosis. Our oncologist told us

that a clinical trial at Children's National might help.

Dr. Packer, Dr. Eugene Hwang, and Nurse Practitioner Lauren Hancock treated us with great compassion. Dr. Packer's hand puppet comforted Jace. The day he took his first step after physical therapy was a great day. Jace fought for 347 days and lived to celebrate his 5th birthday.

Jace's memorial donations to Children's National grew into the Warrior Jace Thompson Foundation. The aim is to find a cure for DIPG. Jace's mantra was, "Can't Stop Me!" We will continue his fight.



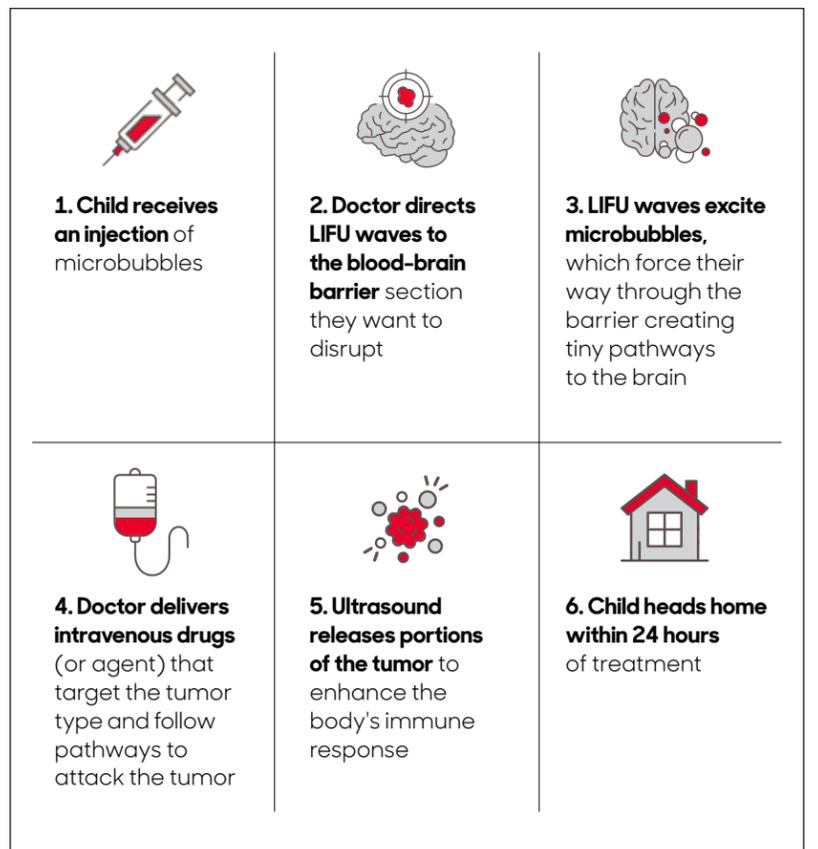
Jace with his family

## New Hope for Children With Deadly Tumors

For too long, patients like Jace (above) have confronted a stark reality about their tumors – few good options. That is changing. In September 2022, Children's National performed the world's first low-intensity focused ultrasound (LIFU) procedure in combination with 5-aminolevulinic acid medication on a pediatric patient.

LIFU safely addresses one of the greatest challenges to effective treatments: the blood-brain barrier. Energy waves direct microbubbles to open this protective barrier for a brief period of time. This offers a crucial window to administer lifesaving drugs.

"Only 1 in 10 children will be alive 18 months after a DIPG diagnosis," says Dr. Packer. "LIFU has the potential to change that paradigm and save more children. This is probably the greatest potential advance that we've seen in decades."



## Unleashing Immune Power

Cellular immunotherapy offers another beacon of hope in our quest to revolutionize brain tumor treatments for kids. This cutting-edge approach harnesses the power of a patient's immune system to unleash modified T cells that target and destroy cancer cells within the brain.

Gifts from philanthropic partners over the last decade catalyzed pioneering work that Dr. Bollard has led in our Center for Cancer and Immunology Research. The new investment supercharges the team's capacity to develop highly personalized therapies using a child's own cells. This is yielding new clinical trials with the potential to reinvent how we care for brain cancer.



## Healing the Broken Part

In between Bennett's monster drives and precision putts, he still receives care at Children's National. Recently, he visited our Hearing and Speech Center for hearing loss that may have resulted from trauma to his brain.

Learning about the phenomenal new philanthropic investments makes him hopeful that more kids with brain tumors will grow up stronger. "When I was little, they took out the broken part of my brain and stitched me up," he says. "Even now, when I walk in the hospital and see those balloons in the atrium, I know it is a special place. I feel safe there."



## Teamwork Without Borders

Clinical trials often represent the only hope for families facing deadly brain tumors. Children's National casts a global net to speed the development of trials and findings.

For example, the Diffuse Midline Glioma-Adaptive Combinatory Trial links 26 institutions in eight countries. Its adaptive model enables pursuit of multiple trial phases simultaneously. This translates into faster results for kids who need solutions today. Key supporters of our leadership within this initiative include ChadTough Defeat DIPG Foundation, The Lilabeen Foundation for Pediatric Brain Cancer Research and RUN DIPG.

In 2021, The Medulloblastoma Initiative, founded by Fernando Goldsztein, partnered with Children's National to launch an international movement to find a cure for relapsed medulloblastoma. This malignant tumor starts in the cerebellum, which is responsible for muscle coordination, balance and movement. The Cure Group 4 Consortium unites

13 laboratories in Canada, the U.S. and Germany. Its findings laid the groundwork for three clinical trials of novel immunotherapies set to open in early 2024. The anonymous investment will bolster core resources at Children's National that strengthen such international efforts for years to come.



Dr. Eugene Hwang (far right) celebrates his professorship in 2023 with the Hughes family in honor of Will (inset)

## A Reminder to Keep Going

"In my office, I have a bulletin board with photos of many of the children, my patients, whom we've lost over the past decade," says Eugene Hwang, M.D., chief of Oncology and the William Seamus Hughes Professor of Neuro-Oncology and Immunology.

The Willie Strong Foundation, with support from the anonymous investment, established Dr. Hwang's professorship in memory of Will Hughes. Will was a patient at Children's National with glioblastoma, a fast-growing central nervous system tumor.

"I keep it there to remind myself who it is we're fighting for," says Dr. Hwang. "A child diagnosed with a brain tumor today doesn't have a single day to wait for a better treatment. We must do more for these kids."

DISCOVER THE ART OF HEALING

# Joy in the Bunny Mellon Healing Garden



Laughter. Sunshine. Flowers. A birthday party for a child who has been in the hospital for months. The Bunny Mellon Healing Garden, dedicated to First Ladies of the United States, offers children, families and staff a peaceful place to breathe fresh air and renew their spirits.

Gifts from the Gerard B. Lambert Foundation, Heather and Andy Florance, CoStar Group and many other donors make this space possible.

It has hosted two weddings, a sunflower music festival, beach parties, winter lights celebrations, the Dunkin' Prom and other special events.

"The natural environment provides a sense of life and hope," says Angelica Bowman, the Healing Garden's team lead activity coordinator.

**"I never expected to feel so happy and connected with other kids while I was in the hospital because I felt secluded in my room. This has been incredible."**

— Olivia, Children's National patient and Dunkin' Prom attendee



**ACE HARDWARE** generously underwrites many activities in the Bunny Mellon Healing Garden.



Scan to watch highlights from Dunkin' Prom

Patient Georgia hugs Angelica Bowman in the Healing Garden  
At left: Olivia with her service dog, Clarence



# 5 WAYS Angelica Brightens Days

Angelica joined Children's National as a volunteer in 2015. "Growing up, I always wanted to help the kids and families in my community," she says. She joined the staff in 2017 on the Child Life and Integrative Care Services team. In 2021, the hospital named her Employee of the Year. "I start every day by asking myself, 'How can I make a child or family's day better?'"

**01** Invites patients for outdoor free play, rock painting or snuggles with a facility dog

**02** Plots scavenger hunts

**03** Decorates a child's hospital room with flower garlands and fairy lights

**04** Organizes open-air yoga and meditation

**05** Invites families to release butterflies and engage in other coping activities

“My son had a lot of firsts at Children’s National. We were in the Healing Garden the first time he felt the sun on his face.”

— Heather,  
Children’s National parent



Angelica with patient Chava  
Inset: Patient Alfie

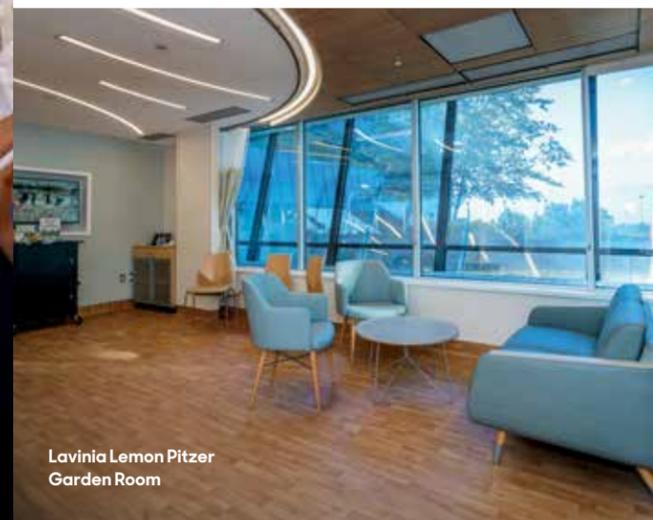
## New Healing Spaces

A recent expansion with two new spaces created more opportunities to experience the Bunny Mellon Healing Garden.

The Lavinia Lemon Pitzer Garden Room opened this September, thanks to the generosity of the Lemon Foundation. This acute care room overlooks the garden, enabling patients medically unable to visit the exterior space to enjoy nature.

The room connects with the hospital's new spiritual care center that provides patients, families and staff with a place to reflect and find comfort. A gift from Panda Cares made it possible.

Both spaces provide vital holistic care to help children heal, says Kathy Gorman, M.S.N., R.N., F.A.A.N., the hospital's executive vice president for Patient Care Services and chief operating officer. "Creating this environment was critical for us to support children and families on their healing journey."



Lavinia Lemon Pitzer  
Garden Room

## MEET THE MOMENT

# Hope Nurse

By Pamela Hinds, R.N., Ph.D., F.A.A.N.

Like many in healthcare and science, I am a very curious person. As a nurse scientist working in a pediatric intensive care unit, I often was surprised by the resilience of seriously ill and injured patients. As I followed them over time, I asked them to teach me what helped them do so well in regaining their health.

They taught me with their one-word answer, indicating their surprise that I even needed to ask: hope. My initial reaction raised another question. How could we ever influence, titrate or measure the effects of something like hopefulness?

To answer this, our team studied hopefulness in healthy adolescents. We also studied those hospitalized for substance abuse, those admitted to residential programs for emotional illness and patients with life-threatening illnesses such as cancer. We asked each about their hopes and what we could do to support them. Then, we listened.

What they shared led us to better understand how we could improve care instead of simply administering treatment.



**“Being known as the ‘hope nurse’ makes me hopeful. It’s one of the greatest professional honors that I might ever have.”**

— Pamela Hinds, R.N., Ph.D., F.A.A.N.

## Ask the Right Question

The mother of a patient knocked on my office door. “Are you the ‘hope nurse?’” she asked. Her daughter, 15, had terminal cancer and could no longer walk. Sitting next to the patient in her wheelchair, I asked my question: “Please, would you share with me what you hope for now?”

She lifted her arms as if she were dancing. “I’m hopeful that tonight I will be a ballerina and pirouette across the stage and that you will be in the audience clapping for me,” she replied. Then, she wilted. “That was just a wish,” she said. “Really, my hope is that tonight I won’t have this much pain and that I can sleep.”

Nurses had been asking for her pain score every four hours using the standardized metric. It indicated no pain. Her answer to the hope question taught us that she had profound pain. With her permission, we changed her care immediately. That night she slept well. She passed away three days later.

When doctors and nurses use our research and the hope question in their work, they tell me the result is an even closer relationship with their patients. They find out more about how treatments make their patients feel. Being known as the “hope nurse” makes me feel hopeful. It’s one of the greatest professional honors that I might ever have.



Nurse practitioner Celicia Little, D.N.P., C.N.P.-P.C., cares for a patient

## Listening Leads to Better Care

**Dr. Pamela Hinds** is one of America’s foremost pediatric nurse scientists. Since 2008, she has served as research integrity officer and executive director for Nursing Science, Professional Practice and Quality Outcomes at Children’s National. She is interim director of our Center for Translational Research. Dr. Hinds is a pediatrics professor at the George Washington University and adjunct professor of Nursing at University of Maryland.

In 2014, Children’s National named her the inaugural William and Joanne Conway Chair in Nursing Research.

Her leadership in research enables us to improve care delivery. A study of how young patients, especially those in cancer treatment, describe their unpleasant symptoms led to the development of a universal list of 62 child-friendly toxicity terms. They are embedded in five global clinical trials. The National Cancer Institute is translating them into seven languages.

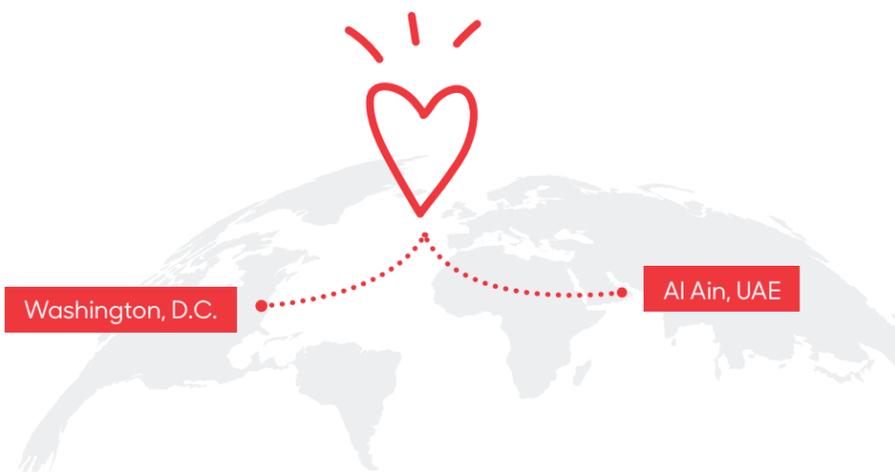
POWER CARE THROUGH PARTNERSHIP

# Children’s National and the United Arab Emirates Share a Global Vision to Improve Pediatric Health

## Two Places, Joined in One Heart

More than 7,000 miles separate Washington, D.C., and Al Ain, an ancient desert city in the United Arab Emirates (UAE). Yet the two cities are joined through the experience of one Emirati girl. Fakhera, 14, was born with a special heart – an enlarged pulmonary artery and other potentially deadly structural problems. Her family’s cross-continental search for help led them to Children’s National for emergency surgery.

Correcting Fakhera’s structural heart defect took years, which included extended stays in Washington. The family became close with cardiologist Gerard Martin, M.D. Fakhera’s earliest memories include running to hug him.



Fakhera also has seen Dr. Martin in the UAE through the Visiting Physicians Program, which brings Children’s National specialists to the UAE to partner with local providers. “Fakhera is an incredible kid,” says Dr. Martin. “She never loses her beautiful smile.”

**“The team saved Fakhera’s life.”**

— Jaber, Fakhera’s father



Noura Al Dhaheri, M.D., the first UAE geneticist trained at Children’s National



## A Global Vision for Care

Children’s National has cared for Emirati children for more than three decades. In 1991, the UAE Embassy opened a medical office in the District of Columbia. Since then, hundreds of young Emiratis and their families have sought care at the hospital. This includes the family of Yousef Al Otaiba, UAE ambassador to the United States. His daughter underwent successful surgery as a baby.

Over time, the medical exchange grew into something far bigger – a deep and broad commitment to improve children’s lives. In 2009, the people of Abu Dhabi – one of seven Emirates that comprise the UAE – made a \$150 million investment to establish the **Sheikh Zayed Institute for Pediatric Surgical Innovation**. Its bold mission is to make pediatric surgery more precise, less invasive and pain free.

The transformational partnership inspired Children’s National to rename its main campus the Sheikh Zayed Campus for Advanced Pediatric Medicine. This is a tribute to the UAE’s late founder, His Highness President Sheikh Zayed Bin Sultan Al Nahyan. The UAE’s generosity reflects the longstanding commitment to children’s health of His Highness Sheikh Mohamed bin Zayed Al Nahyan, president of the UAE and ruler of Abu Dhabi. Each gift has catalyzed and sustained progress in pediatric medicine.

“Our partnership is transforming the lives and health of children in the UAE, U.S. and worldwide,” says Ambassador Al Otaiba.

Fakhera attends the Children’s Ball UAE in Abu Dhabi in 2023. This event at a historic fort, Qasr Al Hosn, under the patronage of His Highness Sheikh Mohamed bin Zayed Al Nahyan, president of the UAE, raised \$1 million to advance pediatric medicine in the UAE.

## Reinventing Pediatric Medicine

The Sheikh Zayed Institute pioneered a new model for innovation in children's health. It brought together bioengineers, scientists and entrepreneurs under one roof to address the unique pediatric needs of children who are not simply small adults. They require distinct treatments and approaches based on their size and development. The institute broke down silos to spark trailblazing inventions that put kids first.

### AlgometRx

Measuring pain can be challenging in children but essential for providing the right care, including proper medication dosages. Julia Finkel, M.D., developed AlgometRx, the world's first device to objectively monitor pain by measuring pupil dilation.



Dr. Julia Finkel



Dr. Karun Sharma

### High-Intensity Focused Ultrasound

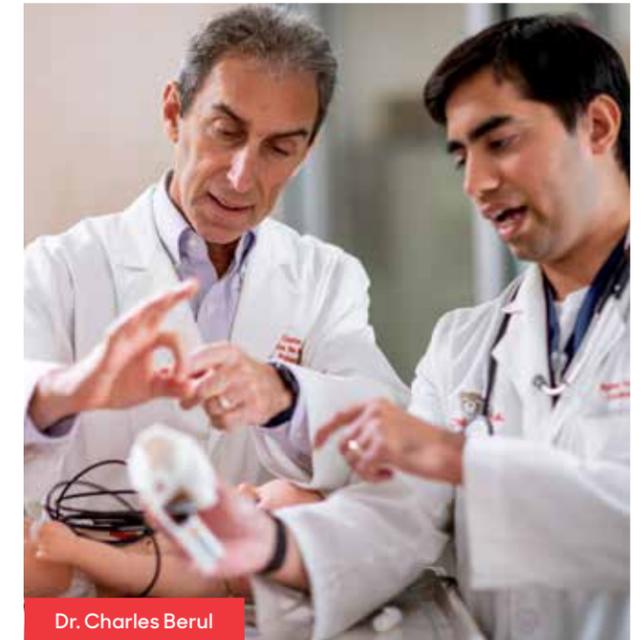
Focused ultrasound represents the frontier of noninvasive surgery since it requires no incision. Karun Sharma, M.D., Ph.D., F.S.I.R., pioneered its use, leading to the first American high-intensity focused ultrasound (HIFU) procedure to treat pediatric osteoid osteoma (bone tumors) as part of a clinical trial. Our team is currently treating patients with sarcoma and brain tumors.

### MGeneRx

Kids with developmental conditions achieve greater lifetime health with early detection. Marius George Linguraru, D. Phil., Connor Family Professor of Research and Innovation and principle investigator at the Sheikh Zayed Institute, worked with Emirati health experts to develop a smartphone-based tool that uses artificial intelligence to identify a child's risk for congenital birth defects.



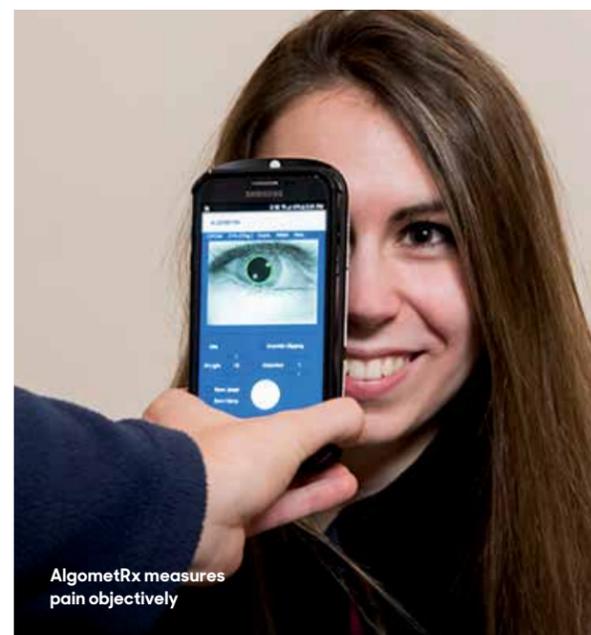
Dr. Marius Linguraru



Dr. Charles Berul

### Tiny Pacemakers for Babies

In 2022, Sheikh Zayed Institute investigator Charles Berul, M.D., The Van Metre Companies Professor of Cardiology, guided the first team of American doctors to insert customized pacemakers into newborns with life-threatening congenital heart disease.



AlgometRx measures pain objectively



**The Sheikh Zayed Institute's bold mission is to make pediatric surgery more precise, less invasive and pain free.**

Today, the Sheikh Zayed Institute plays a leading role within the Alliance for Pediatric Device Innovation. Since 2013, the U.S. Food & Drug Administration (FDA) has directed more than \$16 million to pediatric device development collaboratives led by Children's National. This has launched more than 315 projects, leading to real-world results for children. More than 20 have gained FDA market clearance, FDA approval or European safety approval.

The benefits of the UAE's investments continue to grow. We see them in healthier families, groundbreaking health innovations, new companies, and additional funding from public and private sectors.

**315** medical device projects received early-stage backing and mentorship.





"Make Your Medical Device Pitch for Kids!" competition winners, 2022



Significant investments from the UAE, including a new 2023 gift, promise to fuel more breakthroughs in children's health.

## A Hub for Pediatric Discovery

A \$30 million commitment from the UAE helped us open the Children's National Research & Innovation Campus in 2021.

This first-of-its-kind hub for pediatric discovery harnesses collaboration and science to develop new treatments and medical devices specifically for kids. It convenes global expertise within 160,000 square feet of

laboratory and other space at the former Walter Reed Army Medical Center.

Children's National investigators work alongside inventors and entrepreneurs from JLABS @Washington DC (Johnson & Johnson Innovation's sole startup incubator focused on pediatrics). Our brain tumor researchers team up with colleagues from the

Virginia Tech Cancer Research Group to find new cures.

The campus also houses our Rare Disease Institute – the world's first center of excellence for rare disease care – and the Center for Genetic Medicine Research, offering hope to thousands of families seeking answers for mysterious and often devastating conditions.



Patient Fouz visits a clinic at the Children's National Research & Innovation Campus

## Climbing Higher

Elly loves to climb – at home, on the playground and everywhere she goes. She even talks about climbing mountains. It hasn't always been easy. She was born without thumbs.

Her family visited the Rare Disease Institute for help. Elly tested negative for known genetic disorders, but the question remained: What caused her condition?

She then took part in an ongoing clinical trial facilitated by the world's first Pediatric Mendelian Genomics Research Center at our Research & Innovation Campus. The UAE's founding investment in the campus helped establish the high-throughput computing needed to drive such precision genetic research.

The genetics team also referred Elly to our Plastic and Reconstructive Surgery Team. At 18 months, surgeons transplanted her index fingers to become her thumbs. Elly went home the next day in matching blue casts. Soon she was scaling playground equipment again.

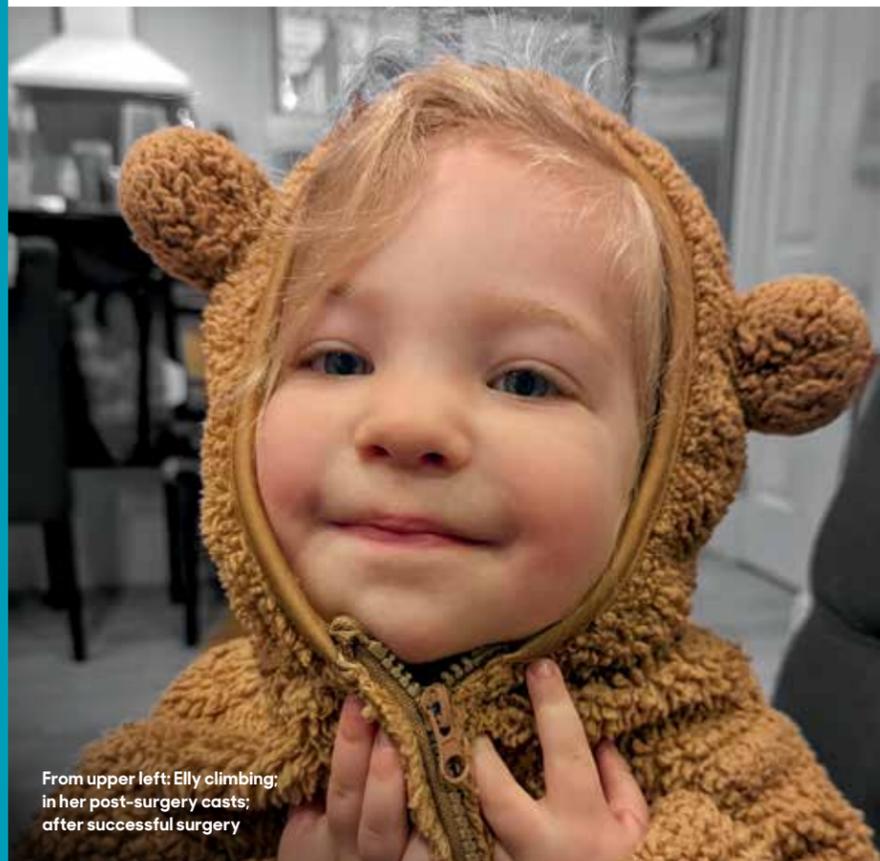
"She can do anything," says her father, Lee. "And as a future mountain climber, she very much needs her thumbs."

**“She can do anything. And as a future mountain climber, she very much needs her thumbs.”**

— Lee, Elly's dad



Technicians conduct research at our Research & Innovation Campus



From upper left: Elly climbing; in her post-surgery casts; after successful surgery



UAE Ambassador  
Yousef Al Otaiba

**The UAE's generosity helped found the Children's National Research & Innovation Campus.**

## GROWN STRONGER

# From Patient to Nurse

## Returning the Compassion



A child anxiously awaits brain surgery. Fortunately, Kyle Wisor is their nurse.

"I'll get down on the patient's level and ask, 'Hey, do you want to see my scar from when I was a kid here?'" Kyle says. "It helps them know they're not alone and feel a sense of relief that I was a patient at Children's National too. I see a light come on that someone understands them."

As a toddler, Kyle had trouble hearing. "My mom would talk to me in the car, but I wouldn't respond from the back seat. She didn't know why. But when she turned around, I'd respond because I was reading her lips."

A specialist diagnosed Kyle with cholesteatoma, a cyst inside the ear that can lead to serious complications, including hearing loss and facial paralysis. He had three surgeries to save his facial nerve starting at age 3. He still had hearing loss but was safe from facial paralysis.

"Without Children's National, I wouldn't have the life I've been so lucky to have," Kyle says. Nearly two decades of compassionate care at the hospital inspired him to become a pediatric nurse with empathy for children who fear the unknown.

After a clinical rotation in our Center for Neuroscience and Behavioral Medicine, Kyle knew it's where he wanted to be. Still, his start was intimidating. "Having the insider view of a former patient, I put a lot of pressure on myself to be a superstar nurse," he says. "But I've realized everyone is learning."



Nurse Kyle cares for Luke, age 7.  
Inset: Kyle as a Children's National patient

Kyle finds new and creative ways to comfort patients who often navigate sensory challenges or developmental delays. "You have to be willing to sit with kids for an extra minute and earn their trust."

Kyle no longer chases superstar status. Instead, he makes kids feel like the stars. "When you show families you care about them, they return that to us." Those moments, he says, inspire him to help the next patient feel like their hospital experience will be OK, just like it was for him.

**“It helps them know they're not alone and feel a sense of relief that I was a patient at Children's National too.”**

— Kyle Wisor, Children's National nurse

CREATE A LEGACY

# Giving Rooted in Experience

*A daughter's journey and an appreciation for pediatric expertise and leadership inspired Betsy Williams and Tom Moore to help redefine how we care for children with epilepsy.*



Betsy Williams and Tom Moore's connection to Children's National began nearly a decade ago when they were searching for answers about their daughter's health. Their experience, along with family ties to medicine and research, inspired a philanthropic partnership with an immediate and lasting impact.

"Our family has always prioritized supporting the right people and places for transformational change," says Betsy. Her family historically has supported research, learning and career development at other academic and nonprofit institutions.

## A Startling Diagnosis

Their experience began when their daughter was diagnosed with epilepsy as a toddler. "She woke up one night and had her first seizure," Tom recalls. "It was a scary moment we will never forget."



Betsy Williams and Tom Moore with Dr. Madison Berl and Dr. William D. Gaillard

Eventually, tests revealed focal cortical dysplasia. This type of epilepsy causes neurons in certain areas of the brain to form incorrectly and can lead to seizures that are difficult to control. William D. Gaillard, M.D., division chief of Child Neurology, Epilepsy and Neurophysiology; director of the Comprehensive Pediatric Epilepsy Program; and associate director of the Center for Neuroscience Research, led her care with the support of his team. "We appreciated how responsive and thorough Dr. Gaillard was," Betsy says.

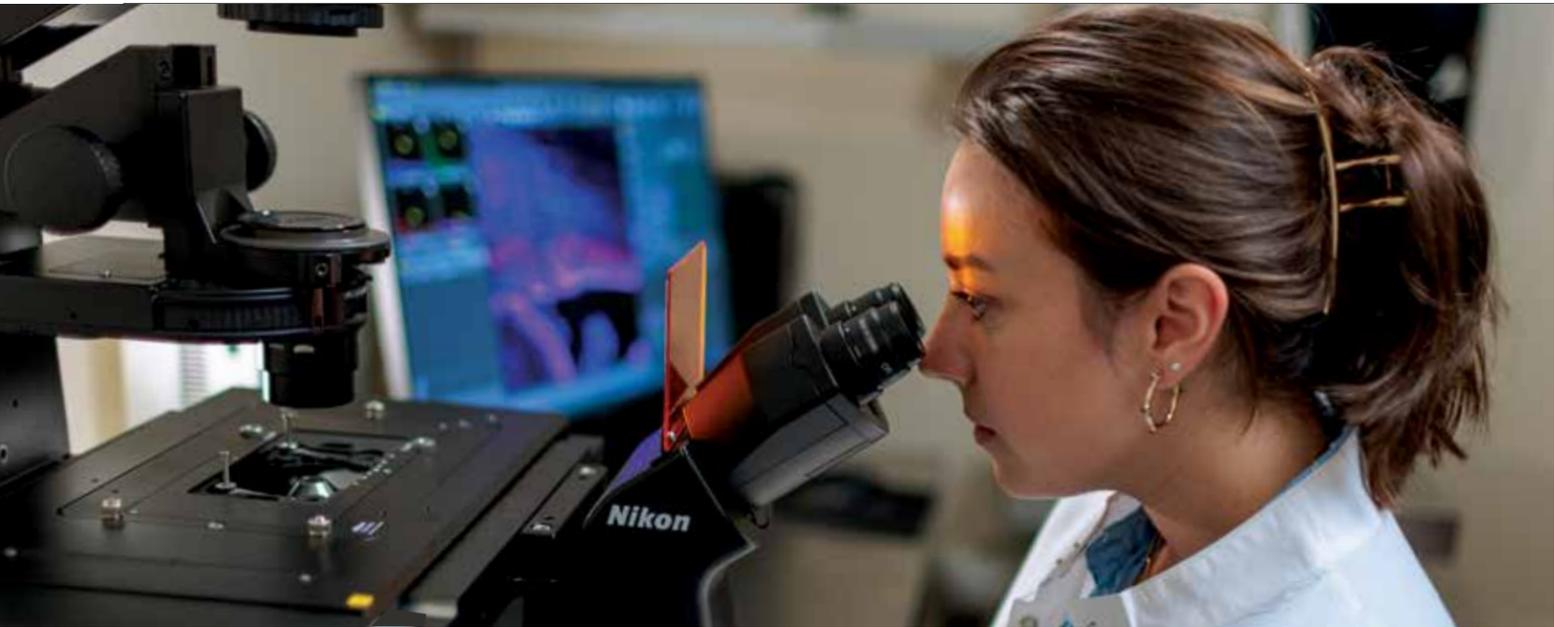
"We recognized immediately that we had one of the world's most knowledgeable experts on our side."

Dr. Gaillard and neurosurgeon Chima Oluigbo, M.D., recommended surgery to remove the dysplasia, or lesion, causing the seizures. Overall, it was a success and reduced their severity. However, this was just the first step in the family's care journey.



**"We recognized immediately that we had one of the world's most knowledgeable experts on our side."**

— Betsy, Children's National parent



## An Enduring Impact

The couple wanted to invest in the team that gave their daughter hope for a healthier future. They decided to make an unsolicited gift to support the epilepsy program at Children’s National. Dr. Gaillard and team used these resources to advance novel research, improve treatments and invest in junior investigators. The research supports cutting-edge imaging studies to better identify the source of seizures, improve surgical precision and develop internationally recognized methods to map and preserve kids’ language abilities.

“It was important to invest in the program’s collective leadership and let Dr. Gaillard and his team decide how to spend the funds,” Betsy says.

The family’s gift also enabled expansion of behavioral health services, including hiring a dedicated psychologist. Our program is one of only a few in the United States that embeds

psychology within patients’ neurology visits. Kids with epilepsy are at a higher risk for anxiety, depression, cognitive issues and behavioral concerns. Neuropsychologist Madison Berl, Ph.D., director of research in our Division of Pediatric Neuropsychology, developed an innovative screening protocol to identify patients who have or are at risk for developing these challenges.

“We have benefited from a consistent team that has provided exceptional, comprehensive care,” Tom says. “We wanted to ensure other families would have that too.”

When the couple’s daughter started elementary school, she experienced a setback. Her seizures ramped up. Her academic development also was concerning. In March 2020, just as the pandemic began, the family spent a week at Children’s National for tests.

“Going to the hospital as the world shut down was one of the hardest decisions,” Betsy

remembers. “But we witnessed the clinicians and staff come together during this unprecedented time to provide exceptional care for our daughter.”

As a result of the testing, the team adjusted her medications and treatment schedule, which improved her daily life. “We’ve learned that with epilepsy, there’s often no easy fix,” Tom says. “We want more families and donors to be aware of this program and the complex care it provides.”

“We witnessed the clinicians and staff come together to provide exceptional care for our daughter.”

— Betsy, Children’s National parent

## OUR COMPREHENSIVE PEDIATRIC EPILEPSY PROGRAM

**Children’s National is a Level 4 epilepsy center with the most specialized care and innovative surgical techniques available.**

A key aspect of our comprehensive, personalized care is our focus on treating the whole child – body, mind and spirit. We address and provide support for the psychological and emotional issues children with epilepsy often experience.



In 2023, U.S. News & World Report ranked us No. 3 in the country and best in the Mid-Atlantic Region for neurological care, including epilepsy, brain tumors and head trauma. Gifts like those from Betsy and Tom help us achieve this honor and reach higher for our patients.

## Investment in Healthier Futures

Today, Betsy and Tom’s daughter is a thriving 11-year-old who enjoys spending time with her 10-year-old sister. Their household buzzes with art projects, an energetic dog, cooking competition shows and trivia about Greek mythology. Through annual assessments with Dr. Berl, the couple continues to focus on their daughter’s social and academic development.

The family’s care journey is ongoing, and their philanthropy is too. In 2022, they made a gift to establish the Professorship in Epilepsy and Neurophysiology at Children’s National. Dr. Gaillard is the first holder of the chair, and it will be named for him in the future.

“If we have learned one thing over the past decade, it is that the people matter as much as the science,” Betsy says. “Honoring Dr. Gaillard’s leadership and investing in his team’s development so they can continue to make a difference for other families like ours is important to us.”

“Betsy and Tom’s gifts have been transformational in allowing us to expand the team’s behavioral health services, invest in the next generation of specialists and stay on the cutting edge of epilepsy care.”

— Dr. William D. Gaillard



Inaugural Professor of Epilepsy and Neurophysiology at Children’s National

GIVE BACK YOUR OWN WAY

# Rallying to Remember



For Barbara Ghadban and her niece, Kelly Fritz, giving to Children's National is a long-standing family affair.

Barbara and her late husband Harry, owners of NVP, Inc., a home building company in Northern Virginia, launched a fundraiser for the hospital 19 years ago to memorialize a family tragedy and give back to the community. The couple raised more than \$760,000 through its NVP Golf Tournament. "What began as a small party in one of our model homes blossomed into an annual October event that everyone rallied around," Barbara says. The final tournament was in 2022.

Kelly lost her newborn son, Jack, in 2016 due to a rare genetic condition. She says the care and compassion of Children's National staff moved her to fundraise for the Race for Every Child. Kelly is a team captain who has raised more than \$184,000 for the hospital. Her four other kids call the event Jack's race. "Out of sorrow," she says, "something beautiful keeps his memory alive."

Barbara and her golf tournament donors have shifted their focus to the Race. "I'm so glad we can support Kelly and continue a family tradition."



Barbara Ghadban and her late husband, Harry, at their NVP Golf Tournament



Kelly Fritz with Dr. Bear at the Race for Every Child, 2020



Team Jack Strong Forever, Race for Every Child

HAPPENINGS

# Our Community Unites for Pediatric Health



Sam, age 12 with mom, Taryn

## Race for Every Child

Patients, families, staff and community members joined the 11th annual Race for Every Child in support of Children's National on Oct. 21 at Freedom Plaza in Washington, D.C., and virtually. There were 5,537 participants in the 5K and Kids Dash. Together, we raised more than \$1.5 million to advance world-class care and discoveries that lead to new treatments and cures.

Sam, age 12, who had heart surgery as a baby at the hospital, has run for several years. His parents, Taryn and Eric, served as 2023 Race co-chairs. "Our insurance paid for the surgery, but we're indebted to Children's National for life," Eric says. "That's how we feel."



Scan to watch highlights from the 2023 Race for Every Child



## Making Strides for Children's Hearts

For 31 years, Van Metre, a champion for children's heart health, has hosted an annual 5K race to benefit Children's National. This event has raised \$3.1 million for patients who need specialized cardiology care. In 2023, it brought together nearly 400 dedicated runners and 130 sponsors to raise a record-breaking \$272,000. Dr. Charles Berul, chief of cardiology, co-director of Children's National Heart Institute and The Van Metre Companies Professor of Cardiology, ran with other team members. "Long-standing philanthropy from Van Metre Companies and its employees propels groundbreaking research and elevates care for children with heart disease," he says. "This event and its many caring participants help our patients reach their full potential."

Learn more at [vanmetre5krun.org](http://vanmetre5krun.org).

The Van Metre 5K race has raised nearly **\$3 million** for kids who need specialized cardiology care.



Dr. Charles Berul, with Dr. Bear and fellow runners, at the Van Metre 5K race

## Driving Discoveries for Kids with Cancer

Our longtime partner Hyundai Hope On Wheels is celebrating 25 years of supporting pediatric cancer research across the nation. In September, Children's National received a grant to advance research for Chimeric antigen receptor (CAR) T-cell therapy. It uses the body's own immune system to target cancer cells. An additional award supports healing music therapy for children that insurance does not cover. Since 2010, the organization has invested nearly \$3 million to benefit our patients and their families.



Hyundai Motor America CEO Randy Parker (left) connects with Aron at the Hyundai Hope On Wheels ceremony



Corporate Advisory Council leader Kevin Reilly at the Hyundai Hope On Wheels Ceremony with 2023 national youth ambassadors

## Light Up Dr. Bear

This holiday season, when you donate, your gift lights up special Dr. Bears at the hospital. Patients and their families will see your compassion and support. It will give them a reason to believe in the magic of the holidays while they're in the hospital dealing with illness or injury. Light up Dr. Bear from wherever you are and see other donors across our community do the same.

“People should care about Children’s National because kids are the next generation, so we need to care for them as much as we can.”

— Naomi, Children’s National patient



Scan this QR code, donate and watch your gift light up Dr. Bear.



Naomi, 2023;  
Inset: Naomi, age 4



## Dancing Again

By Naomi, age 9  
Children’s National patient

I love to dance hip-hop and run track. When I was little, I ran around a lot. But when I was 4, I woke up with my legs hurting. The pain spread to my arms and soon I couldn’t walk.

Doctors at Children’s National told us I had acute flaccid myelitis. It affects nerve cells in the spinal cord. I spent two weeks in the pediatric intensive care unit. The people there are nice and

always made it easier when I had to have a shot or fluid drawn. They let me watch cartoons and hold my parents’ hands.

They made it possible for me to walk again. Now I can do all the things I love, including riding my bike, and I’ve kind of got life planned out. People should care about Children’s National because kids are the next generation, so we need to care for them as much as we can.

## Helping Alfie Thrive

By Heather,  
Children’s National parent

It’s hard to relax when your baby is critically ill. Alfie was born with life-threatening sepsis following possible meconium aspiration. At 2 months, doctors transferred him to the neonatal intensive care unit (NICU) at Children’s National.

We were terrified new parents. The transport team was kind and confident and eased our worries. In the NICU, the admitting nurse immediately exclaimed she was in love with Alfie, which further eased our worries. His team included specialists in pulmonology,

cardiology, gastroenterology and neurology. They gave us hope that our son would one day have a normal life. Overall, he spent 44 days on extra-corporeal life support and 72 days on a ventilator.

Alfie finally came home at 4 months. He turns 2 in December and loves to dance, eat, play and try any food we put in front of him. We will have a joyful Christmas with family who have waited so long to spend the holiday with our little miracle baby.

The people at Children’s National pull off the most incredible things. They gave Alfie – and all the babies they save – the chance to grow up and change the world.



Above: Heather holds Alfie in the NICU  
Bottom: Alfie with Light up Dr. Bear, 2023

## Meet New Members of the Children’s National Hospital Foundation Board of Directors

Children’s National looks to community leaders and recognized experts to serve as ambassadors for the hospital and help us advance our mission. We were honored to welcome the following members to the Foundation Board in 2023.

### KATHIE WILLIAMS Chair



Kathie Williams, a longtime Children’s National supporter and volunteer leader, began her service in 2007 with The Board of Visitors (now Founders Auxiliary Board). She has served in a variety of roles including president, treasurer and executive director for A Vintage Affair, an annual fundraising gala that celebrated its 25th year in 2023.

She previously was a board trustee at Connelly School of the Holy Child, chairing both the Admissions and Board Affairs Committees. Kathie served in the East Wing of the White House for First Lady Laura Bush as a member of Volunteer Services.

Kathie holds a B.S. from Thomas Jefferson University, formerly known as Philadelphia College of Textiles and Sciences. She is married to Mike Williams, chair of the Bearacuda RE Board and past chair of Children’s National Medical Center Board. The couple has two adult children.

### FERNANDO GOLDSZTEIN Director



Fernando Goldsztein is a Brazilian businessman and veteran of the real estate industry. He was commercial director of Goldsztein Participações until 2009, when Cyrela Brazil Realty acquired it. He currently serves on Cyrela’s board. He holds a B.A. from Pontificia Universidade Catolica do Rio Grande do Sul and M.B.A.s from Fundacao Dom Cabral and the Massachusetts Institute of Technology.

In 2021, Fernando founded The Medulloblastoma Initiative (MBI). Its bold vision is to eradicate medulloblastoma, the most common malignant pediatric brain tumor, and save thousands of children’s lives.

MBI established the Cure Group Four Consortium with the guidance of principal investigator Dr. Roger J. Packer of Children’s National. This pioneering research network links 13 laboratory teams in the U.S., Canada and Germany to accelerate progress. It aims to develop a new therapeutic treatment and standard protocol of care for Group 4 medulloblastoma within 18 to 24 months, faster than the traditional three- to five-year timeline.

### PAUL GRAYSON Director



Paul Grayson is a longtime supporter of Children’s National and also serves as chair of the Foundation Advisory Board.

He joined BG Ventures as a principal in 2014. He sources and executes new acquisitions, ushers leasing activities, manages major capital improvement projects and raises capital.

Prior to BG Ventures, Paul worked at The Carlyle Group in Washington, D.C.; Walker & Dunlop; and JP Morgan Chase.

Paul received his B.S. with a double major in economics and human organizational development from Vanderbilt University (cum laude) and his M.S. in Real Estate from Massachusetts Institute of Technology.

### TIMOTHY R. LOWERY Director



Timothy R. Lowery is a vice president with the global commercial real estate investment firm Hines, based in New York and Washington, D.C.

He serves as general manager of CityCenterDC and oversees management, operations, marketing and tenant relations for the landmark, mixed-use development. Timothy is responsible for the coordination of all uses, including office, retail, residential rental, condominium and hotel. Under his leadership, CityCenterDC is recognized as one of the nation’s most transformative downtown projects. It has garnered awards from the real estate, retail and marketing spheres.

These include MAXI@ Awards from the International Council of Shopping Centers, ADDY@ American Advertising Awards from the American Advertising Federation, three EMMY@ Awards from The National Academy of Television Arts and Sciences and multiple DowntownDC Momentum Awards.

### Children’s National Hospital Executive Leadership

**Michelle Riley-Brown, MHA, FACHE**  
President & CEO

**Donna Anthony, M.P.H.**  
Vice President & Chief of Staff

**Nathaniel Beers, M.D., M.P.A., F.A.A.P.**  
Executive Vice President, Community and Population Health

**Catherine Bollard, M.D., M.B.Ch.B.**  
Interim Executive Vice President and Chief Academic Officer  
Interim Director, Children’s National Research Institute

**Denice Cora-Bramble, M.D., M.B.A.**  
Chief Diversity Officer

**Jeffrey Dome, M.D., Ph.D.**  
Senior Vice President, Center for Cancer & Blood Disorders

**Kathleen Gorman, M.S.N., R.N., F.A.A.N.**  
Executive Vice President of Patient Care Services  
& Chief Operating Officer

**Mary Anne Hilliard, Esq., R.N., F.A.A.N.**  
Executive Vice President & Chief Legal Officer

**Aldwin Lindsay, M.B.A.**  
Executive Vice President & Chief Financial Officer

**Matt MacVey, M.B.A.**  
Executive Vice President & Chief Information Officer

**DeAnn Aston Marshall, M.H.A.**  
President, Children’s National Hospital Foundation

**Jessica Menter**  
Executive Director, Corporate Governance and Strategic Engagement

**Anthony Sandler, M.D.**  
Senior Vice President & Surgeon-in-Chief  
Joseph E. Robert, Jr., Center for Surgical Care  
Director, Sheikh Zayed Institute for Pediatric Surgical Innovation

**Rahul Shah, M.D., M.B.A.**  
Senior Vice President, Children’s National  
Hospital-Based Specialties Center

**Linda Talley, M.S., R.N., NE-BC, F.A.A.N.**  
Senior Vice President & Chief Nursing Officer

**Elizabeth Wells, M.D., M.H.S.**  
Senior Vice President, Center for Neuroscience  
and Behavioral Medicine  
Neurologist

**David Wessel, M.D.**  
Executive Vice President, Chief Medical Officer  
& Physician-in-Chief

### Children’s National Hospital Foundation Executive Leadership

**DeAnn Aston Marshall, M.H.A.**  
President

**Amy Boger**  
Chief of Staff and Board Relations

**Julie Butler**  
Vice President, Corporate and Special Events

**Shelley Cooke**  
Associate Vice President Major and Principal Gifts

**Tin Pham**  
Associate Vice President Finance and Donor Services

**Leslie Schrader**  
Vice President and Chief Marketing Officer

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Chair

**Barbara Lopez Kunz**  
Vice Chair

**Ramu Potarazu**  
Treasurer

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**Jonca Bull, M.D.**

**Toni Bush**  
**Amy Freeman**

**Michael Jones**  
**Jason Levien**

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**Linda Rabbitt**

**Jimmy Reyes**  
**Mark Rouchard**

**David Strickland**  
**Caroline Van Vleck, M.D.**

**Michael Ward**  
Directors

**Michelle Riley-Brown, MHA, FACHE**  
President & CEO

### Children’s National Hospital Foundation Board of Directors

**Kathie Williams**  
Chair

**Amy Baier**  
Chair (through Sept. 30, 2023)

**Debra Coleman**  
**Fernando Goldsztein, M.B.A.**

**Paul Grayson**  
**Thomas Lloyd**

**Timothy Lowery**  
**Jimmy Reyes**

**Mei Xu**  
Directors

**Michelle Riley-Brown, MHA, FACHE**  
President & CEO

**Horacio Rozanski**  
Children’s National Board Chair



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beginnings*

# Children's <sup>♥</sup> Ball 2024

A gala to celebrate the  
future of children's  
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*Brighter  
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*Save the Date*

Saturday, April 13, 2024 | The Wharf & The Anthem