2023 ANNUAL REPORT





#### Dear Friends,

Your partnership in our mission propels us into a transformative period for Gillette Children's. By harnessing cutting-edge technology and fostering a culture of excellence, we are expanding our reach and setting new global standards of care. Your generosity, combined with the commitment of our extraordinary teams, is driving us toward breakthroughs that will enhance the lives of the children we serve and advance care worldwide. We are not just envisioning a brighter future for our patients —we are actively building it.

We reflect on 2023 as a time of acceleration:

- We centered the voices of families to revolutionize our research, shifting their role from participants to active and equal collaborators.
- We advocated, at every possible level, for changes to policy that will improve the lives of children living with brain, bone, and movement conditions and their families.
- We leveraged advancements in technology to unlock the power of millions of clinical data points and developed novel strategies to share our knowledge with the world.
- We built global coalitions to transform the way the world cares for patients living with rare diseases.

We celebrate these achievements and keep pushing forward. We remain, as we have throughout Gillette's history, undeterred in pursuit of our vision. Every day, the brightest minds and fiercest advocates work at Gillette, to build a world in which every child can create their own story. As you explore our achievements and milestones from the past year, we extend our deepest gratitude for your support. Together, we are forging new pathways of discovery, innovation, and inclusion.

Barbara Joers
President and CEO

Kathy Tune Board Chair

Kathleen June



President and CEO, Barbara Joers pictured with board chair, Kathy Tune.

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Deb Gordon Kathy Tune

Barbara Joers Scott Ward, Chair

Kara Lazarus Kamran Maki

Taylor Marcus

#### 2023 Community Members of Board Committees

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Phil Becker

Arthur Beisang, MD

Dave Bestler

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Sean Elliott, MD

Diane Harper

Scott Robinson

#### Vision

A world in which every child is able to create their own story.

#### Mission

In collaboration with patients, families, and partners, we redefine what is possible for children with brain, bone and movement conditions through clinical leadership, research, and global advocacy.



We are grateful for the extraordinary service of the members of our 2023 board of directors, philanthropy board, and committees. Through their dedication and leadership, we illuminate the future of Gillette Children's.

# Stories of Impact

So often, families take long journeys searching for the right care for their child. When they arrive at our door, they feel they've come home. We are here, ready to care for brain, bone, and movement conditions needing specialized expertise. Your support helps every child create their own story.

# Early Evaluation Gives Ernesto a Strong Start

Shortly after he was born, Ernesto Prieto was diagnosed with cerebral palsy, which describes a group of disorders that affect a person's ability to move and maintain balance. His mother Dalia and their family's pediatrician knew Ernesto would need the services of a strong medical team to help him thrive and reach his potential. When Ernesto was about 6 months old, Dalia took him to an Infant and Toddler Development Evaluation appointment to meet with Gillette experts who are specialists in the identification of developmental delays. This team includes physiatrists, neurologists, and trained therapists who analyze the results of multiple assessments and work with families to create a comprehensive treatment plan. Now 2 years old, Ernesto is getting stronger with the help of his multidisciplinary team at Gillette. He enjoys zooming his gait trainer around the Gillette Burnsville therapy gym under the guidance of his physical therapist. "I love coming to Gillette," Dalia says. "I enjoy the therapists and they do a great job of telling me what they're working on with Ernesto and how I can help him at home."





# **Spine Solutions Help Zayne Thrive**

When she heard her 4-year-old son, Zayne, would need spine surgery, Jesse Stegeman admits feeling "terrified." The mother of two has been through a lot of medical complications with Zayne, who was born with a rare genetic disorder. "At one of Zayne's first appointments at Gillette the team did a big workup and discovered a slight curve in his spine, and they thought it could be scoliosis," Jesse recalls. Gillette is a nationally and internationally recognized leader in research and care for pediatric orthopedics and the treatment of pediatric spine conditions, including scoliosis. At first, Zayne wore a Thoraco-Lumbo-Sacral Orthosis, a brace made of plastic and foam that extends from a child's upper armpits to just below their hips. As Zayne grew, his thoracic curve continued to progress. His pediatric spine surgeon at Gillette suggested Zayne undergo surgery using magnetically controlled growing rods. Zayne's family is incredibly thankful for the care he receives care from a large, multispecialty team of experts at Gillette. "The doctors are awesome," Jesse beams. "The support staff, nurses, schedulers, and everyone is just wonderful, and they truly care."

#### Rare Disease Care Gives Holli a Path Forward

Approximately one out of every five Gillette patients has been diagnosed with a rare disease. Holli Harter is one of those patients. When her parents, Devin and Richie, took Holli to her first pediatrician visit, her doctor recommended that they see specialists who could follow up on his concern that Holli had osteogenesis imperfecta.

Osteogenesis imperfecta (OI) is a rare genetic condition that causes a defect in a protein found in bones, leading to fragile bones that can break easily. Gillette offers a multidisciplinary Osteogenesis Imperfecta Clinic where patients see a dedicated OI team, including experts from specialties like pediatric endocrinology, orthopedics, physical medicine and rehabilitation, audiology, occupational therapy, physical therapy, and social work. Holli's parents felt relief after meeting with a Gillette physician. "He confirmed Holli's diagnosis, but also said 'You do not have a fragile baby. She's going to be ok. Here's what's going to happen," says Devin. The expert guidance helped Holli's family chart a path forward with a full team of specialists to support them. Coordinated care has helped with everything from managing Holli's medical needs to enabling her to enroll in daycare and school along with her friends.





# Collaborative Epilepsy Care Brings Confidence to Wesley and His Family

When Wesley Raymaker experienced his first seizure just after his 4th birthday, his parents Paul and Jackie immediately knew where to go. They were already confident in their care team at Gillette after navigating his cerebral palsy diagnosis. It is estimated that about 4 in 10 children with cerebral palsy also have epilepsy. For the Raymakers, it was a relief to find coordinated, collaborative care that addressed his needs for both diagnoses. "The providers have an expertise level that makes you feel comforted," notes Jackie. Now 9 years old, Wesley is a dynamic and happy child with a deep love of sports. His seizures are now well-controlled and he continues to meet regularly with a care team that he's known for much of his young life. "We have such a deep feeling of gratitude towards Gillette," says Jackie. "I just find it inspiring—just how much energy goes into helping every child."

#### Our 2023 Impact

# Gillette Children's served patients from 8 countries, 43 US states, and all Minnesota counties



27,920 unique patients recieved care at Gillette



3,999 patients served have cerebral palsy



4,060 patients served have spine conditions



11,890 virtual visits helped patients connect to our expertise

Top conditions seen (by patient volume):

Cerebral Palsy
Limb Length Discrepancy
Developmental Dysplasia of Hip
Epilepsy
Idiopathic Scoliosis



\$2.9 million helped families in need of care through the Gillette Assistance Program



140 active research studies worked to unlock new discoveries



81 peer-reviewed publications shared knowledge with the world

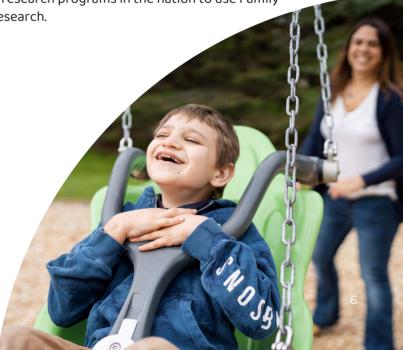


#### Advancing Discovery, Innovation and Inclusion

- As a founding member of the International Hospital Federation's Global Rare Paediatric Disease Network, Gillette worked with hospitals around the world to share experiences and best practices to enhance services for children with rare diseases and their families worldwide.
- Tom Novacheck, MD, assumed the role of Chair of Gillette Children's Cerebral Palsy Institute, which champions innovation in clinical care, forward-thinking research, and patient advocacy.
- Gillette launched the Health Care Transition Learning Collaborative, a groundbreaking project aimed at advancing the transition from pediatric to adult health care for children and youth with special health needs.
- Gillette introduced the Children's Spine Institute, led by Tenner Guillaume, MD, highlighting the organization's ongoing commitment to innovative, personalized pediatric spine care.
- Gillette's Board of Directors established the Gillette Children's Philanthropy Board to drive philanthropic efforts.

- Orthopedic surgeons Ann Van Heest, MD, and Deborah Bohn, MD, collaborated on the children's book "Proud To Be Me," published by Gillette Children's Health Care Press and funded by the James House, MD, MS, Fund for Hand and Upper Extremity Excellence at Gillette Children's.
- Gillette successfully advocated for patient and community needs at the state and federal levels, including increased out-of-network care access for children with rare diseases, development of inclusive playgrounds, and significant funding for cerebral palsy research.
- Rewaa Elgazzar joined Gillette as a groundbreaking Rare Disease
   Diversity Coalition (RDDC) Research Fellow. The fellowship empowers
   the next generation of leaders to work in the rare disease space and
   address health disparities among people of color with rare diseases. As
   an RDDC member, Gillette strives to alleviate the disproportionate
   burden of rare diseases on communities of color.

Gillette's Family Engagement in Research Council launched, creating a
collaborative, best-practice approach to research. In this innovative
program, Lived Experience Partners provide critical and unique expertise
about "life outside the clinic walls," allowing research teams to consider
more perspectives and increase the impact of research results. Gillette is
one of only a few research programs in the nation to use Family
Engagement in Research.





# Driving Innovation Through Research

Gillette has been at the forefront of treating children who have conditions affecting the musculoskeletal and neurological systems since 1897. We consider it our responsibility to use our experience to conduct clinical research that will improve treatment options for children who have disabilities—not only for those treated at Gillette but for children around the world. Thank you for helping elevate our commitment to clinical research.

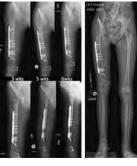
### **Exploring New Limb-Lengthening Solutions**

New research, titled "Motorized Plate Lengthening of the Femur in Children: A Preliminary Report," was published in the Journal of Pediatric Orthopaedics by Gillette pediatric orthopedic surgeons Mark Dahl, MD, and Andrew Georgiadis, MD. The study prospectively collected data on a new limb-lengthening implant.

In this study, seven patients aged 2–9 underwent femoral lengthening surgery using a magnetic lengthening plate.

This research touches on a difficult aspect of limb lengthening treatment in young children with smaller bones. Small bones present a challenge because they still have open growth plates and anatomically may not be able to support an implant that goes inside the bone until a child's pre-adolescent or adolescent years. Currently, most literature represents external fixation as the best choice for lengthening small bones. "External fixators have unique complications both physically and psychologically for a child and family," Dr. Georgiadis says. "We want to decrease the burden on the family undergoing limb lengthening as much as possible, so we try to use these internal methods whenever we can."





Imaging from a 9-year-old girl with fibular hemimelia and congenital short femur who underwent magnetic plate lengthening.

Asking Unique Questions for a Rare Patient Population

The Seating Pressures in Neuromuscular Scoliosis pilot study is led by principal investigator Dan Miller, MD, and supported by spine researchers Sara Morgan, PhD, and Zelphia Brown, MPH, and members of the Gillette Children's orthotics, prosthetics and seating team, including Nick Anderson, DC, ATP, and Joe Berdan, ATP.

Supported by the Pediatric Orthopaedic Society of North America (POSNA) St. Giles Young Investigator Award, the study is investigating the effects of spinal fusion surgery on measures of seating pressures and patient-reported seating comfort in non-ambulatory children with neuromuscular scoliosis associated with cerebral palsy. For these patients, spinal curvatures can have significant effects on health, comfort, skin integrity, and quality of life.

# Predicting Pain for Children with Cerebral Palsy

Can we predict when someone might feel pain? Gillette Children's is doing important research to answer this question for children who have cerebral palsy (CP) through our groundbreaking "Predictors of Pain" study.

Throughout the study, the team will track how kids experience pain – how strong, how often, and for how long – both leading up to surgery and after surgery. The research team is driven to understand and help manage pain for children with cerebral palsy.

This study, supported by a grant from the National Institute of Health, is led by senior clinical scientist Chantel Burkitt, PhD, along with clinical scientist Liz Boyer, PhD, and Tom Novacheck, MD, head of Gillette Children's Cerebral Palsy Institute.



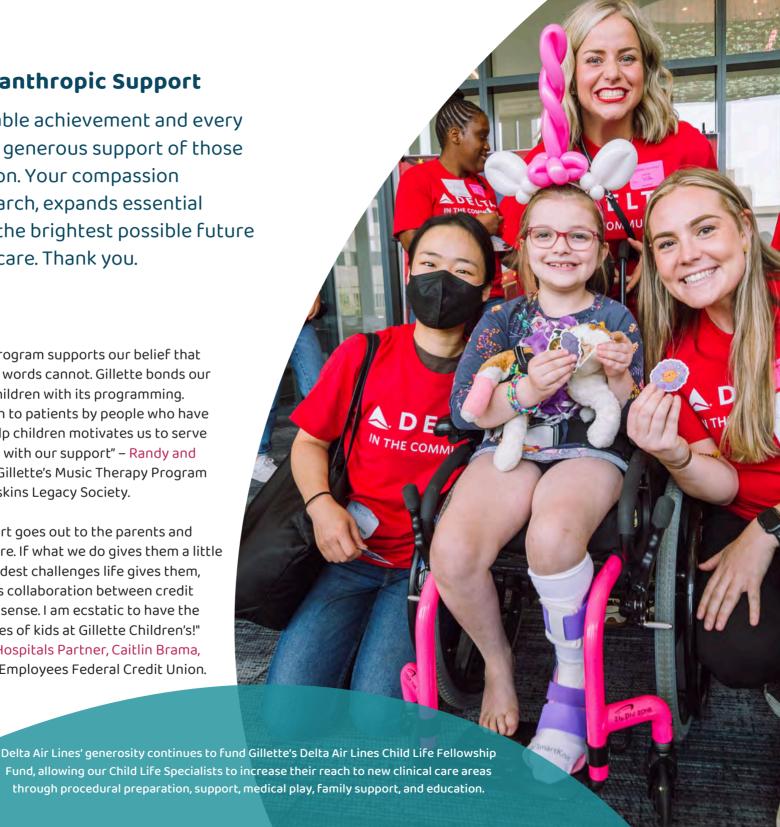
# The Power of Philanthropic Support

Behind every remarkable achievement and every breakthrough lies the generous support of those who give to our mission. Your compassion accelerates vital research, expands essential services, and creates the brightest possible future for every child in our care. Thank you.

# **Donor Perspectives**

"Giving to the music therapy program supports our belief that music speaks when and where words cannot. Gillette bonds our need to improve the lives of children with its programming. Seeing firsthand the care given to patients by people who have found their calling in life to help children motivates us to serve their nurturing and inspiration with our support" - Randy and Marcy Betcher, supporters of Gillette's Music Therapy Program and Members of the Jessie Haskins Legacy Society.

"Being a parent myself, my heart goes out to the parents and families who need specialty care. If what we do gives them a little relief through some of the hardest challenges life gives them, what more could I ask for? This collaboration between credit unions and Gillette just makes sense. I am ecstatic to have the privilege to help impact the lives of kids at Gillette Children's!" - Children's Miracle Network Hospitals Partner, Caitlin Brama, President/CEO of Farm Credit Employees Federal Credit Union.







A Children's Miracle Network Hospital

## gillettechildrens.org

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Gillette Children's is a global beacon of care for patients with brain, bone, and movement conditions that start in childhood. Our research, treatment, and supportive technologies enable every child to lead a full life defined by their dreams, not their diagnoses. To learn more about Gillette, visit gillettechildrens.org.

Gillette Children's was named in honor of orthopedic surgeon Arthur Gillette, MD, who founded our organization as the nation's first public hospital for children who have disabilities. Grounded in that founding mission, we continue to collaborate with patients, families, and our partners in clinical leadership, research, and advocacy to set the standard of care and opportunity for children with complex medical challenges.

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