

Gillette

Partners in Care

JOURNAL

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FALL 2023

FOCUS:

Introducing the Gillette Children's Spine Institute

See how we are transforming
pediatric spine care

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On the cover: Zayne Stegeman attends a Gillette appointment to lengthen the magnetic growing rods in his spine. Read Zayne's story on page 11.

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Chief Medical Officer & Executive Vice President, Clinical Affairs

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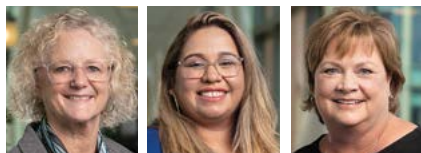
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Spine Institute: Tenner Guillaume, MD

About Our Journal

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Micah Niermann, MD
Chief Medical Officer & Executive Vice President of Clinical Affairs

Dear Colleagues,

On behalf of Gillette Children's, I'm proud to announce the formation of a new Spine Institute.

The establishment of the Gillette Children's Spine Institute reflects our organization's steadfast commitment to excellence in the care of children with brain, bone, and movement disorders. The idea of Gillette began with Jessie Haskins, a young woman with scoliosis who advocated for dedicated, expert care for children with physical disabilities. When Gillette opened its doors in 1897, our first patient was a young boy named Royal Gray, who was successfully treated for his spine deformity from tuberculosis.

Since the very beginning, Gillette has been at the forefront of pediatric spine care. With the Spine Institute, we will now be poised to rapidly and continuously redefine the cutting edge in spine care so that every child can tell their own story just as Royal was able to do.

In this issue, you'll read more about the Spine Institute and our research regarding neuromuscular scoliosis. You'll also meet Zayne, a patient who benefits from our unique spine expertise. As always, we are honored to partner with you in the care of your patients with brain, bone, and movement disorders.

Cerebral Palsy Institute Taps Andrea Bushaw, PhD, to Be Dyad Leader

Gillette has named the second dyad leader for the Cerebral Palsy Institute. **Andrea Bushaw, PhD, APRN, CPNP**, director of Clinical Transformation, will partner with **Tom Novacheck, MD**, to advance clinical excellence, research, innovation, and advocacy for people who have cerebral palsy.

Dr. Novacheck, orthopedic surgeon, was named Cerebral Palsy Institute Chair earlier in 2023. He is also medical director of Integrated Care Services.

The dyad leadership model pairs physicians with non-physician administrators to guide the transformation and shared vision. For the Cerebral Palsy Institute, Gillette uniquely aligns clinical with transformational expertise to translate and implement evidence into cerebral palsy clinical practice.

Dr. Bushaw will continue to lead the Clinical Transformation team, which oversees the translation and implementation of existing evidence and new knowledge into clinical practice — resulting in improved patient care, job satisfaction, quality, and safety.

She is a member of AACPD, the International Family Nursing Association, a Patient-Centered Outcomes Research Institute Ambassador, and an Adjunct Clinical Assistant Professor School of Nursing at the University of Minnesota.



Gillette Children's Launches Health Care Transition Learning Collaborative

Gillette Children's is excited to announce the Children and Youth with Special Health Needs Health Care Transition Learning Collaborative (HCT LC), a groundbreaking project aimed at advancing pediatric to adult healthcare transition for children and youth with special health needs. Supported by a grant of \$160,000 from the Minnesota Department of Health's (MDH) Child and Family Health Division, this 14-month initiative began in June 2023.

Led by **Tori Bahr, MD**, and **Rhonda Cady, PhD**, in partnership with the National Alliance to Advance Adolescent Health/Got Transition, the HCT LC strives to achieve a seamless, equitable, and inclusive transition process.



Tori Bahr, MD



Rhonda Cady, PhD

Supported by a grant of \$160,000 from the Minnesota Department of Health's (MDH) Child and Family Health Division, this 14-month initiative began in June 2023.

The HCT LC will leverage a virtual "all teach, all learn" approach to facilitate monthly learning opportunities and multidisciplinary discussions. These virtual sessions will consist of expert lectures on various transition-related topics followed by interactive case studies where audience members and faculty engage in collaborative problem-solving. With 10 planned sessions, each lasting approximately one hour, participants will gain valuable insights on enhancing their clinics, hospitals, programs, and overall state practices related to healthcare transition.

"The Children and Youth with Special Health Needs Health Care Transition Learning Collaborative is a critical step toward ensuring that our healthcare system meets the unique needs of children and youth with special health needs," Dr. Bahr says. "This collaborative effort will drive positive change, improve outcomes, and create a more inclusive and equitable transition process."

Ann Van Heest, MD, Chosen as President of the American Orthopedic Association

Gillette surgeon **Ann Van Heest, MD**, has been elected as president of the American Orthopedic Association for 2023-24. The organization's mission is to engage the orthopedic community to develop leaders, strategies, and resources to guide the future of musculoskeletal care. Dr. Van Heest is a recognized expert in the field of hand and upper extremity orthopedics and an accomplished researcher with contributions to more than 50 papers and presentations. Much of her research has a focus on innovations in surgical simulation. She completed her advanced training (fellowship) in hand surgery at Harvard University.

In addition to clinical care, she is a professor at the University of Minnesota Orthopedics Department. Dr. Van Heest is an active member of the American Board of Orthopedic Surgery Board of Directors, American Academy of Orthopedic Surgery, American Society for Surgery of the Hand, Pediatric Hand Study Group, and the Congenital Hand Anomalies Study Group. She is board certified in orthopedic surgery and hand surgery.



Ann Van Heest, MD



Gillette Welcomes New Providers



Matthew Severson, MD, joined Gillette Children's in September as the newest fellowship-trained Pediatric Rehabilitation Medicine physician. He joined the team after completing his PMR fellowship at Gillette Children's. Dr. Severson attended medical school at the University of Minnesota and did his residency in Physical Medicine and Rehabilitation at Mayo School of Graduate Medical Education.



Elizabeth Davin, PA-C, joined the Orthopedics team in July 2023. She came to Gillette from CVS Minute Clinic. Davin attended the Massachusetts College of Pharmacy and Health Sciences, where she got her master's in physician assistant studies. She specializes in scoliosis care.



Za'Nii Roundtree and her family chose Gillette Children's for her neuromuscular scoliosis and kyphosis care.

Introducing the Gillette Children's Spine Institute

Transforming pediatric spine care

Embarking on a global mission to redefine pediatric spine care, Gillette Children's Spine Institute is transforming care through the convergence of collaborative sub-specialty clinical care, patient-centered research, and the expansion of health literacy. The collective energy of these focal points will propel innovation that changes the care of children's spine health.

Tenner Guillaume, MD, pediatric orthopedic surgeon, was named Chair of the Gillette Spine Institute. He says, "The creation of the Spine Institute signifies Gillette Children's ongoing commitment to innovative, personalized, pediatric spine care. Our team is advancing spine health through three tenets: advancing evidence-based clinical practices, patient-centered research, and empowering parents with education to make confident decisions. At the intersection of these pillars, we transform care for children with common to complex spine conditions."



Tenner Guillaume, MD

Specialized Conditions & Care

Gillette Children's Spine Institute is a premier destination for children with routine, complex, or rare spine conditions.

1. Spinal Conditions: Scoliosis, Kyphosis, Spondylolysis, Spondylolisthesis, Cerebral Palsy, Scheuermann's Disease, Spina Bifida, Spinal Cord Injuries, Tethered Spinal Cord, Growing Spines
2. Spinal Test/Treatments
 - o EOS X-ray, CT scans, MRIs, Ultrasounds
 - o Non-operative: bracing, casting, physical therapy
 - o Surgical: Fusion, Vertebral Body Tethering, Magnetically Controlled Growing Rods, Spinal Cord Detethering

“The creation of the Spine Institute signifies Gillette Children’s ongoing commitment to innovative, personalized, pediatric spine care. Our team is advancing spine health through three tenets: advancing evidence-based clinical practices, patient-centered research, and empowering parents with education to make confident decisions.”

–Tenner Guillaume, MD

The Future of Spine Care Is Highly Personalized

The future of pediatric spine care lies in a highly personalized approach. It involves tailoring evidence-based treatments and interventions to specific needs, complexity, circumstances, and preferences. The Spine Institute is at the forefront of this transformative shift by enhancing our patient-centered model. Gillette Children’s considers each child’s unique circumstances, aspirations, and preferences as a part of the assessment and treatment plan.

Converging the Power of Clinical Expertise, Research, and Health Literacy

As one of the nation’s largest spinal care providers, our patients benefit from a team of subspecialty experts. Together, this interconnected expertise is reshaping the care for children with spine conditions.

1. Clinical Expertise

With more than 125 years of experience, the Spine Institute is committed to delivering state-of-the-art clinical care tailored to the unique needs of each child. From routine to rare and complex, experienced spine and pediatric orthopedic surgeons, neurosurgeons, physical therapists, onsite orthotics, and other specialists collaborate to develop personalized treatment plans that prioritize the child’s well-being and long-term health.

Advanced technologies, novel surgical techniques, and enhanced imaging work together with extensive clinical expertise — for example, higher quality imaging with lower dosage radiation X-rays.

Often, patients at Gillette have very complex spinal curvatures and anatomy. Traditionally, pediatric orthopedic surgeons had to rely on imaging such as X-ray, MRI, and CT alone, which take 3-dimensional (3D) patients and convert their spines into 2-dimensions (2D). Surgeons then utilized these 2D images to create a 3D understanding of the spine in their mind’s eye to plan interventions.

Dr. Guillaume says, “Thanks to the Spine Institute’s clinical partnerships, we now have the technology to create life-sized, printed 3D models of our patients’ spines preoperatively. This allows us to truly understand and study the patients’ spines to tailor surgeries better and maximize safety. These 3D models can then be employed in the operating room to guide our surgical plans and treatments in real time. We have truly entered a new era of pediatric spine surgery.”



Tenner Guillaume, MD, speaks with Owen Earl before surgery.

How to Refer

Partnering with Gillette Children’s Spine Institute is easy.



In-Person
Appointment

Patient seeking a
second opinion?
Gillette Children’s
Online Written
Second Opinion
is a convenient,
swift service.



Online Second
Opinion

2. Patient-Centered Research

Gillette uses research to push the boundaries of what is possible in spine care. Each study is designed with the patients and their families in mind, seeking to identify treatments that maximize patient outcomes while minimizing the impact of treatments rendered. Through a close, collaborative relationship between researchers and the clinical team, insights are translated into new clinical pathways and opportunities for patients. ▶



Eduardo Beauchamp, MD, reviews X-rays in clinic before adjusting Zayne's magnetically driven growing rods. Read more about Zayne Stegeman's spine care on page 11.

Our clinical and research teams collaborate with national and international experts in multisite studies and registries (like the Pediatric Spine Study Group) to ensure that we are contributing to the greater body of knowledge in the treatment of pediatric-onset spine conditions in ways that will impact care. Today, more than 120 groundbreaking studies are published and underway to unlock new insights and develop innovative spine treatments. **Learn more about ongoing neuromuscular scoliosis research on page 8.**



Learn about patient-centered research at Gillette.

3. Empowering Health Literacy

Gillette Children's Spine Institute is committed to providing both parents and healthcare providers with valuable resources that allow families to make informed and confident decisions for their children, whether they are dealing with common or complex pediatric spine conditions.

For parents, our educational materials demystify complex spine symptoms, conditions, and treatment options, with a special focus on preparing for surgery and home care after surgery. This detailed education enables communication that builds trusted relationships between our spine care team and their patients.

Leading the Way

From routine to rare, over 25 pediatric spine disorders (congenital, developmental, traumatic) are treated at Gillette Children's Spine Institute. It is a beacon for children with spine care needs as one of the world's largest centers dedicated to pediatric spine care.

At a Glance:

3,763	120
Spine patients	Total research studies

Source: 2022 Gillette Data

For providers, Continuing Medical Education (CME) is offered to ensure providers stay updated with the latest research, advanced options, and evidence-based practices in pediatric spine health. For established family medicine providers or pediatricians, our spine team takes care to offer referral guides and red flags for spine conditions they may encounter in their practice. Gillette also offers Spine Research Fellowships and other clinical experiences.



View education opportunities.

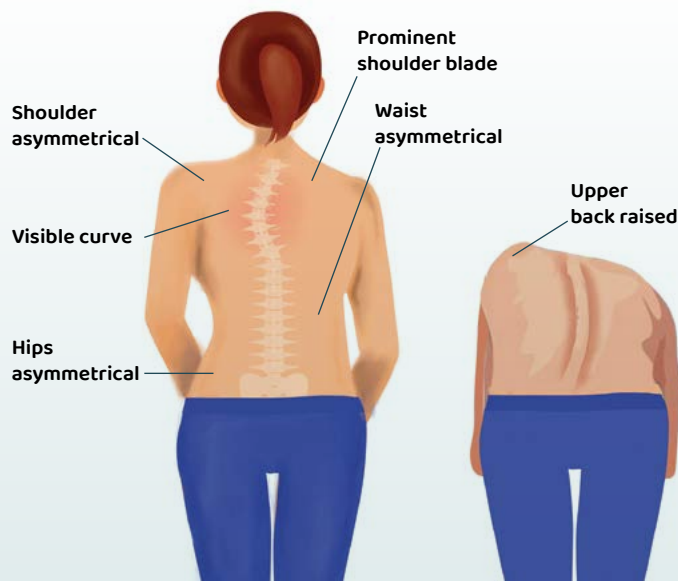
Scoliosis Referral Guide

How to screen and when to refer

Gillette Children's treats the majority of children in Minnesota with spinal conditions. Our six spine surgeons perform more pediatric scoliosis surgery than any other hospital in the five-state area. Because we see the full spectrum of spine cases, from mild to severe, all patients benefit from our spine team's depth of experience, no matter their complexity.

Identifying Scoliosis

Scoliosis is one of the most common pediatric spine conditions you may encounter in your day-to-day practice. When you suspect your patient may need a pediatric spine specialist for their scoliosis, there are some easy signs and symptoms you can look for.



Understanding Scoliosis Treatments

An important consideration when recommending treatment of scoliosis symptoms is the degree of curvature the patient is experiencing.

Degree of Curve	Course of Action
<10°	Observe clinically over time
10-20°	Periodic X-rays
20-45°	TLSO or Nighttime bracing
>45°	Surgical intervention; fusions at any skeletal maturity
Any curvature	SCHROTH (scoliosis-specific exercises)
Further evaluations needed to qualify	VBT (vertebral body tethering); skeletally immature

How to Screen:

Adam's Forward Bend test at every well child check:

- If >7° rotation, PA and lateral full spine X-rays recommended
- If curve on X-ray <10°, may observe clinically
- If curve on X-ray 10°-15°, repeat X-rays in six months

When to Refer:

- X-ray shows curve >15°
- Repeat X-ray shows increase in curve
- X-ray shows abnormal spine anatomy

Gillette providers are available to consult or to co-manage with a primary care provider at any point in a patient's curve progression.

Our Spine Providers

Abby Anderson, PA-C

Eduardo Beauchamp, MD

Amy Jo Beebe, MA, APRN

Elizabeth Davin, PA-C

Tenner Guillaume, MD

Danielle Harding, PA-C

Daniel Miller, MD

Kyle Miller, MD

Megan Moffatt, MS, APRN

Katie Peltz, PA-C

Joseph Perra, MD

Laura Tillman, DNP, APRN

Walter Truong, MD



The pressure mapping mat generates a three-dimensional image of the participants' seating pressures and how the body connects with the seating surface.

Neuromuscular Scoliosis Study Asks Unique Questions for a Rare Patient Population

Novel Study Aims to Determine the Impact of Spinal Curvatures on Sitting Comfort and Health in Patients with Neurologic Conditions

The focus of research at the Gillette Spine Institute is investigating neuromuscular scoliosis (i.e., lateral curvature of the spinal column in patients with neurologic conditions). For these patients, spinal curvatures can have significant effects on health, comfort, skin integrity, and quality of life.

Spinal fusion surgery is typically performed for patients with severe curvatures in hopes of improving or maintaining lung function, seating comfort, and health-related quality of life. Currently, "success" of spinal fusion surgery is often based on radiographic markers of spinal curvature and balance even though the clinical significance of these variables with respect to seating, comfort, and skin integrity is poorly understood.

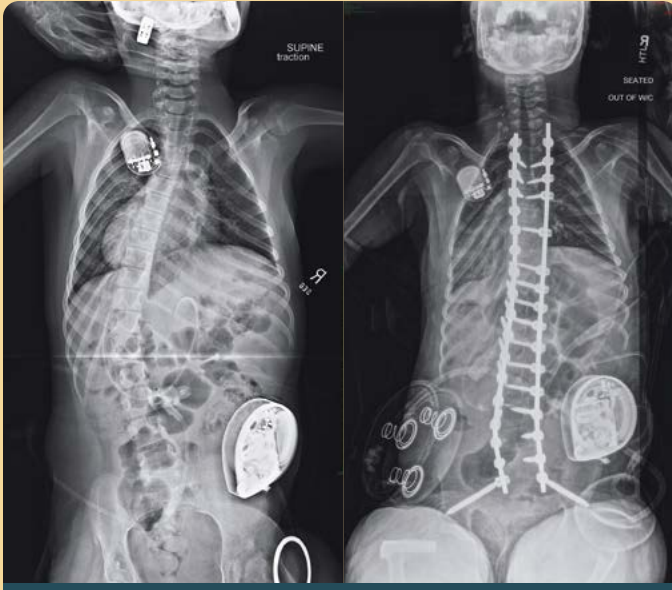
Seating Pressures in Neuromuscular Scoliosis

The Seating Pressures in Neuromuscular Scoliosis pilot study is led by principal investigator **Dan Miller, MD**, and

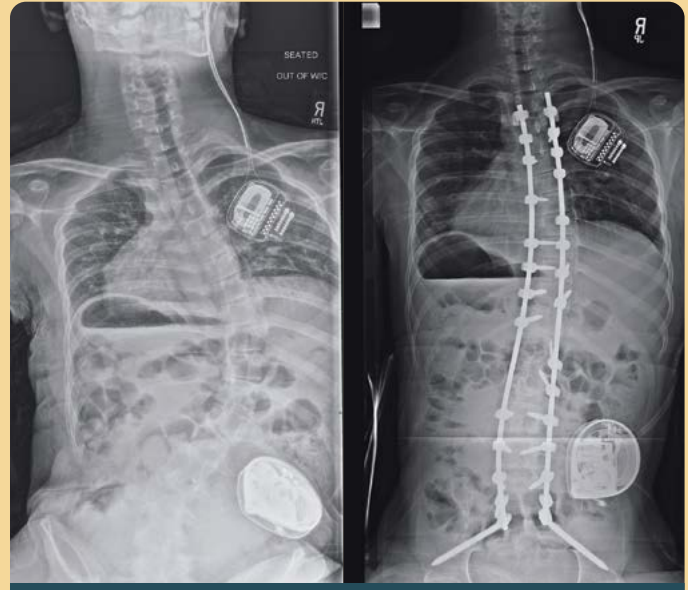
supported by spine researchers **Sara Morgan, PhD**, and **Zelphia Brown, MPH**, and members of the Gillette Children's orthotics, prosthetics and seating team, including **Nick Anderson, DC, ATP**, and **Joe Berdan, ATP**.

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.

To achieve these objectives, non-ambulatory patients aged 10 to 21 years with neuromuscular scoliosis undergoing spinal fusion surgery are evaluated before and after surgery. These evaluations are intended to assess if spinal fusion surgery changes the way people with neuromuscular scoliosis sit in a wheelchair, including the amount of pressure on the skin and their overall sitting comfort.



Patient A



Patient B

Neuromuscular scoliosis is an abnormal curving of the spine in children with an underlying neuromuscular condition such as muscular dystrophy, spina bifida, spinal muscular atrophy, or cerebral palsy. These changes in nerve and muscle function reduce the ability to physically support a growing spine. Often, spine fusion is recommended for patients with severe curvature, as seen in the before and after X-rays above.

During these evaluations, the study team utilizes an Xsensor pressure mapping mat. The pressure mapping system gathers detailed information about the average, peak, and minimum pressure experienced by participants as they sit on a flat surface. By integrating this quantitative data with radiographic imaging and patient reported outcomes surveys from the participants' parents, the research team gains a more comprehensive understanding of the seating impacts of spinal fusion surgery.

Patient-Reported Outcomes Are Key

Dr. Morgan believes patient-reported outcomes are integral to the pilot study, providing valuable insight into the patients' experiences. She says, "We're focused on the outcomes and treatments that matter most to patients. We work to engage patients with spinal conditions and their families in our research program to ensure that our research is meaningful in the lives of the patients that we treat."

Results from this line of research will facilitate preoperative counseling and shared decision-making with patients and their caregivers, as well as possibly improve elements of patient care before and after spine surgery. This data will be relevant not only to pediatric patients with neuromuscular scoliosis, but also to patients with spinal cord injury and adult patients with other neuromuscular conditions and spinal deformities.

Enrollment in the study is underway, and the team anticipates enrolling a total of 30 participants. With a two-year follow-up period, the Seating Pressures study is expected to conclude in 2026.

"We're focused on the outcomes and treatments that matter most to patients. We work to engage patients with spinal conditions and their families in our research program to ensure that our research is meaningful in the lives of the patients that we treat."

-Sara Morgan, PhD

What is the incidence of neuromuscular scoliosis?

25%

Patients with hemiplegic cerebral palsy (two limbs involved)

80%

Patients with quadriplegic cerebral palsy (four limbs involved)

67%

Patients with spinal muscle atrophy (SMA)

90%

Patients with Duchenne muscular dystrophy

Source: Scoliosis Research Society



Delivering Quality Cerebral Palsy Care

Gillette Children's Cerebral Palsy Institute Puts Patients First

Dr. Marcie Ward's goal is to guide cerebral palsy care at the Institute to address not just the needs, but the aspirations of the patients and their families. For some patients, that means community activities like adaptive water skiing would be embedded into their care plan.

The Gillette Children's Cerebral Palsy Institute is dedicated to helping provide the most promising future possible for individuals who have cerebral palsy (CP). Gillette looked toward **Marcie Ward, MD**, pediatric rehabilitation medicine physician, and **Meghan Munger, PhD**, director of Outcomes at Gillette, to help guide the multidisciplinary Care Delivery team at the Institute.



Marcie Ward, MD

The Care Delivery group ensures that every part of CP care at Gillette is continuously changing for the better and adopting the clinical best practices that the rest of the Cerebral Palsy Institute teams have researched and validated. "Leading this team allows me to bridge the gap between clinical practice and the work of the Knowledge Translation and Research teams that are seeking to provide even better care options for Gillette patients," Dr. Ward says.



Meghan Munger, PhD

Patient Navigation Pilot Breaks New Ground

One such care option that builds on Gillette's collaborative CP care model is the Patient Navigation pilot. "For families in the pilot program, our teams proactively organize and manage the extensive care needs and appointments so that families can participate in streamlined care — that means fewer trips to the clinic with more accomplished at each visit," Dr. Ward says.

"Although there is research evidence to support care management and care coordination, we must study how well it works, and under which circumstances it works best, at Gillette," according to Dr. Munger.

In the coming year, the Care Delivery team will be able to see preliminary results for the Patient Navigation pilot program. From there, the team will share evidence-based practice guidelines that can impact families beyond Gillette walls, even teaching other health systems and creating change at the policy and insurer level.

Looking to the Future

Both Dr. Munger and Dr. Ward see great promise in the work they're accomplishing at the Institute. "I view Gillette as a learning health system in its infancy, where research is more rapidly integrated into practice," Dr. Munger says. "We're well on our way toward systematically gathering our own evidence that informs a sustainable, family-centered care model with measurable, positive impact on patients and families that choose our care."

"The overarching hope is that all patients with cerebral palsy will receive well-coordinated, streamlined care in a timely fashion to maximize their development, function, and ability," Dr. Ward says. "On a personal level, my dream is that the Cerebral Palsy Institute will allow all our patients to participate in sports and recreational programs to maximize their overall participation in life."



Read more about the work of the Cerebral Palsy Institute at gillettechildrens.org/CPi

The Magic of Magnetic Rods

Surgically placed rods that can grow with a child

Zayne Stegeman and his family live 60 miles northwest of Minneapolis in Mora, MN, and come to Gillette for rare disease and spine care.

Four-year-old Zayne was born with cri-du-chat syndrome, a rare genetic disorder caused by missing pieces on chromosome 5. The characteristics of a baby born with cri-du-chat include a small head size (microcephaly), low birth weight, craniofacial malformations, and developmental delays.

When Zayne was about a year old, his primary care doctor referred him to Gillette.

Time for interventions

Zayne's mother, Jesse Stegeman, recalls at one of her son's first appointments the Gillette team discovered a slight curve in his spine and recommended he be monitored for scoliosis.

Eventually, Zayne's scoliosis got to the point where pediatric spine surgeon, **Eduardo Beauchamp, MD**, and his team suggested care and interventions.

Dr. Beauchamp initially put Zayne in a full-time Thoraco-Lumbo-Sacral Orthosis (TLSO). This type of brace is made of plastic and foam and extends from a child's upper armpits to just below their hips.

"Zayne wears his brace 23 hours a day," Jesse says. "Surprisingly, he tolerates it really well, but the brace did not stop the progression of his curve."

Controlling the Curve

As Zayne continued to grow and develop, Dr. Beauchamp suggested Zayne undergo surgery using magnetically driven growing rods known as MAGEC® rods.

Gillette is an international leader in this procedure that involves implanting two rods in a patient's back to straighten a patient's spine. MAGEC rods are one of the first ways to treat early onset scoliosis.

The MAGEC rods are surgically placed on either side of the spine to help control the curve. The rods can be lengthened

with a remote control every three to six months in a doctor's office. One of the main benefits of this treatment is that the rods can expand as the child grows, often eliminating the need for repeated surgeries.

A Strong Team for Zayne

Gillette is a nationally and internationally recognized leader in pediatric orthopedics and in the treatment of pediatric spine conditions, including scoliosis.

Jesse is incredibly thankful Zayne receives care from a large 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."

Because the magnetic rods can be lengthened via a remote control, multiple surgeries are often eliminated.



"The support staff, nurses, schedulers, and everyone is just wonderful, and they truly care."

—Jesse Stegeman

Gillette

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JOURNAL

Partners in Care Journal is a publication of Gillette Children's.

The team at Gillette Children's knows that expertise regarding complex conditions is almost as rare as the conditions themselves. We strive to share our knowledge with providers across the world to positively impact patient care for generations to come. That's why we partner with you at every stage of your referral journey.

We respond daily to comments and questions submitted via email at providerrelations@gillettechildrens.com

To refer a patient



Call 651-325-2200
855-325-2200 (toll-free)



Refer online at
gillettechildrens.org/referral

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Consequences of Fall Study Recommends Easy Accessibility Tips

Elizabeth Boyer, PhD, clinical scientist at Gillette Children's, recently wrapped up her conclusions in studying falls in individuals with cerebral palsy (CP).

Clinical Results:

Based on almost 400 participants aged 5-76 years, Dr. Boyer and colleagues found that 86% of individuals fell at least once in the past year. This is about three times higher than the general U.S. adult population, who is 65 years or older. Falling becomes less common as ambulatory individuals with CP go from young childhood to adulthood. Furthermore, gross motor ability — often classified by Gross Motor Function Classification System (GMFCS) level — is associated with how often people fall. Individuals in GMFCS level II and III fall more than individuals of GMFCS level I, who have the least impairment.

Many injuries were reported, with the most common being stitches on the face/head (22% of participants), fracture (19%), sprained knee/ankle

(16%), and concussions (13%). The psychological repercussions of falls, like embarrassment, loss of confidence, fear, or anxiety about falling, were nearly universal and had profound impacts — some said the psychological effects were more concerning than the physical effects.

What can society do differently to help mitigate falls?

Answers from study participants included:

- Declutter walkways, including removal of throw rugs
- Install more grab bars and handrails
- Don't wrap handrails with holiday decorations
- Shovel and salt your sidewalk in a timely manner
- Don't rush people
- Ask first before jumping in to help someone who has fallen



Watch the
Consequences of Falls
webinar featuring
preliminary results
from the study:
Cerebral Palsy Research
Network webinar