

Gillette

Partners in Care

JOURNAL

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SUMMER 2024

Treating Cerebral Palsy One 'Robot Test' at a Time

How the Gillette James R. Gage
Center for Gait and Motion Analysis
helps children who have CP

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On the cover: CP patient Owen Sather, 8, had his first gait and motion analysis at Gillette when he was 4 years old.

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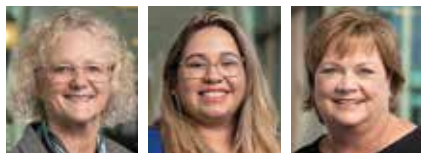
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Editor: Teddi Marzofka

Contributors: Greta Cunningham, Chad Dillard, Emma Willms

Design: Unlock Health

Provider Relations Liaisons



Vicki Kopplin Reyna Staats Tara Swedberg

Contact the team at providerrelations@gillettechildrens.com



Climate Change Disproportionately Impacts Individuals Who Have Disabilities



Gillette's commitment to environmental sustainability is deeply rooted in our work, because we know climate change poses unique challenges for people who have disabilities and complex medical conditions, making them disproportionately affected by its impacts:

Climate change impacts

- During extreme weather events like hurricanes, floods, or wildfires, those who have limited mobility may experience challenges accessing resources or evacuating because infrastructure and transportation systems may not be properly equipped to accommodate their needs.
- Climate-related disasters may cause disruptions to electricity, putting those who rely on specific medical equipment or assistive devices at risk.
- Rising temperatures and worsening air quality may pose significant health threats to those who have respiratory disorders or heat sensitivity.
- Individuals who have disabilities often face higher rates of poverty,

unemployment, and housing instability — factors that may intensify the impact of climate-related disasters.

To help address the impact of climate change on the lives of our patients, Gillette is taking bold steps to address it.

In 2022, Gillette Children's signed the U.S. Department of Health and Human Services' (HHS) pledge to lower greenhouse gas emissions and build a more climate-resilient infrastructure. The pledge calls for a 50% reduction in greenhouse gas emissions by 2030 and net zero by 2050.

Gillette has already successfully implemented changes in areas across our hospitals and clinics, including switching to recyclable and compostable products and improving waste disposal methods.

Currently, hospitals are some of the biggest emitters of greenhouse gases and account for 8.5% of total U.S. emissions.

Bringing Smiles and Surgical Skills to Vietnam

Three Gillette Children's surgeons recently traveled to Vietnam on a mission trip to help physicians in that country learn techniques to better serve patients.

Gillette craniofacial and plastic surgeon **Jo Barta, MD**, pediatric neurosurgeon **Patrick Graupman, MD**, and pediatric urologist **David Vandersteen, MD**, spent a week in Vietnam as part of a mission for the International Pediatric Specialists Alliance for the Children of Vietnam (IPSAC-VN). The organization was founded by a surgeon who came to the U.S. as a refugee in her childhood. IPSAC-VN brings surgeons from all areas of expertise and many countries to help train young Vietnamese surgeons.

"Working with IPSAC-VN allows me to share my knowledge and skill with other physicians, who then can go on to use that knowledge and skill for providing greater care to their patients. I always come back with a few new skills I learned from them too," Dr. Barta adds.

"The healthcare resources in Vietnam are limited and the access to healthcare or the ability to pay for certain procedures is more



Gillette craniofacial and plastic surgeon, Jo Barta, MD, examines a patient in Vietnam.

difficult for people there," Dr. Barta says. "The amount of time spent training for a medical specialty is much longer in the U.S. than in Vietnam. The surgeons in Vietnam need to be very creative and adaptive so they can achieve the best care possible for their patients with the resources they have."

Dedicated doctors throughout Gillette help put our mission and vision into action to help improve the lives of children around the world.



Read more about board-certified craniofacial and plastic surgeon Jo Barta, MD, at gillette.mn/jo-barta-md.

The Gillette Assistance Program's Impact



The Hunt Family, with Jonah (center) and Asher (far left).

Gillette Children's is committed to ensuring access to care for every family who walks through our hospital and clinic doors. Although Gillette works with many private and public insurance providers, not all of them cover all the care services provided to patients. Some patient families

have high deductibles, high copayments, or no insurance coverage at all. In these cases, patients or their families are encouraged to

apply for the donor-supported Gillette Assistance Program (GAP).

Through GAP, we've been able to provide a critical boost for families juggling medical costs, the need for services not covered by insurance, and in the case of the Hunt family, multiple family members needing care.

Jonah and Asher Hunt have both had multiple hereditary exostosis since birth. Now 14 and 18, they visit Gillette for regular

checkups to monitor the bone growths caused by the condition. Both have surgeries when the growths interfere with their bodies' development as they age.

The Hunts worked with Gillette's patient financial representatives to create a payment plan that covered Jonah and Asher's ongoing medical needs and fit their family's financial needs. This plan ran smoothly until Jonah and Asher's father, Jason, was diagnosed with cancer. Suddenly there was a lot more for the Hunt family to manage when it came to healthcare and finances.

In some cases, Gillette has information necessary to determine presumptive eligibility for GAP. GAP funds are then used to provide full or partial discounts on medical balances related to their care. It was this scenario that led to some good news for the Hunt family, who one day received word from Gillette that they'd be receiving a financial boost through GAP.

"When I heard that our bill for Jonah's surgery was wiped out to a balance of zero, I was speechless and in tears," says Shelly, Jonah and Asher's mom. "Any little bit of help with medical bills is a blessing to our family."

Learn more about the Gillette Assistance Program or donate





Brennan models her TLSO.

Brace Yourselves

Gillette researchers create predictive model of scoliosis bracing outcomes

Clinical scientist **Michael Schwartz, PhD**, and certified orthotists **Kristin Smith, CO, CTO**, and **Brian Benish, CO**, are proud to share the culmination of 14 years of hard work in validating Thoraco-Lumbo-Sacral Orthoses (TLSOs) as a treatment option with predictable outcomes for children who have idiopathic scoliosis.

Usually worn full-time or a minimum of 18 hours per day, a TLSO is considered the “gold standard” for stopping or slowing curve progression and preventing spine surgery as long as it’s worn as prescribed. Now, thanks to Dr. Schwartz, Smith, and Benish’s dedication and expertise, clinicians and their patient families can easily see how wear time — the amount of time a patient wears their brace — affects their curve progression, and therefore, their risk for needing a spine surgery in the future.

“We already knew from the landmark BRAIST study that a TLSO can be effective in managing a scoliosis curve,” Smith explains, “But what no one has really quantified until now is how much benefit

a child would get per hour of TLSO wearing while taking into account their age, skeletal maturity, or initial angle of their curve.”

Thermochrons measure brace adherence

The first, most critical step of this yearslong endeavor was making sure that the thermochrons were delivering data that could be accurately and precisely applied to a patient’s TLSO wear time.

The team had to think about how the temperature of the brace can fluctuate even if it’s not being worn. For example, maybe on the body the thermochron logs a certain temperature, but when you throw the brace in the trunk of the car or leave it on the side of the tennis court, environmental factors can allow for higher temperatures to log too.

To combat this tricky problem, the team developed a small study where eight participants kept detailed diaries of their TLSO wear time to compare to the thermochron data points and come up with an acceptable range of temperature fluctuation. This data validation was published in *Spine* journal in 2012.

“There are lots of wrong ways to slap a thermometer on a device for research,” Dr. Schwartz jokes. “Without this critical validation stage and a robust algorithm, we wouldn’t be able to say our data means what we say it means — it would be entirely conjecture.”

A quick data extrapolation showed that up to 25% of patients may not have to wear their brace for as many hours a day as the “gold standard” recommends.

The thermochrons logged temperature data from the TLSOs 24 hours a day, seven days a week, in 15-minute intervals.



Optimized Bracing Recommendations Can Make Patients' Lives Easier

Speak to any preteen prescribed a TLSO and they'll tell you: It's not cool and it's not comfortable. So how can this TLSO outcomes study change patients' experiences with bracing?

"After 14 years of researching this topic, the risk model brings tears to my eyes, but the other interesting takeaway from this dataset was the ability to see which patients we were 'overbracing'; or who may have worn their TLSO for more hours than they needed to," Smith says.

A quick data extrapolation showed that up to 25% of patients may not have to wear their brace for as many hours a day as the "gold standard" recommends.

"That's part of what makes this predictive algorithm so powerful — we can immediately impact treatment recommendations for new scoliosis patients by showing them their expected outcome at any given wear time for their degree of curve and skeletal maturity."



Kristin Smith, CO, CTO



Stay up to date with the latest Gillette spine research at gillette.mn/spine-institute.

Turning temperature data into predictive technology

The thermochrons logged temperature data in 15-minute intervals 24/7 for 200 participants being treated for idiopathic scoliosis at Gillette Children's and Twin Cities Spine Center. Enrollment began back in 2010.

Smith says, "It sounds like a long time, but studying outcomes in scoliosis just takes a long time. We enrolled patients for five years, the TLSO treatment for each child can take another few years, and then we wanted to follow them for two more years after that to make sure we were getting an accurate snapshot of their treatment outcomes, including their ending curve angle and any surgeries that were still necessary."

"Involving the second center was important to us as researchers because it shows that our results are significant across different orthotists and with different TLSOs, not just specific to the Gillette Orthotics team," adds Dr. Schwartz.

With the data set, the study team was able to create an algorithm that produces a dynamic graph of an individual's risk of surgery that changes as their wear time changes. "The app allows a family or a provider to select a child's initial curve and their skeletal maturity, then toggle the hours of wear time to see how different brace adherence would change their individual outcome," Dr. Schwartz explains.

The app is a huge boon for clinicians and families alike, allowing both to look at evidence-based outcomes based on the patient's individual situation. For example, an adolescent who is skeletally immature with a 30-degree curve could see that 18 hours of wear time lowers their surgery risk significantly as compared to 12 hours per day. It empowers individuals and families to make informed decisions on their treatment plans.

The future of wear time research

Schwartz and Smith are excited about the prospect of additional avenues of research for TLSO wear time. The team already looked at more factors that could predict risk based on their current data, like apex of the curve and curve pattern, but did not find any significant correlation.

"The next step could be to look at the brace itself," Smith says. "By researching how the braces are built or how much correction is in the brace, clinicians would be able to inch toward optimal treatment recommendations."



Michael Schwartz, PhD

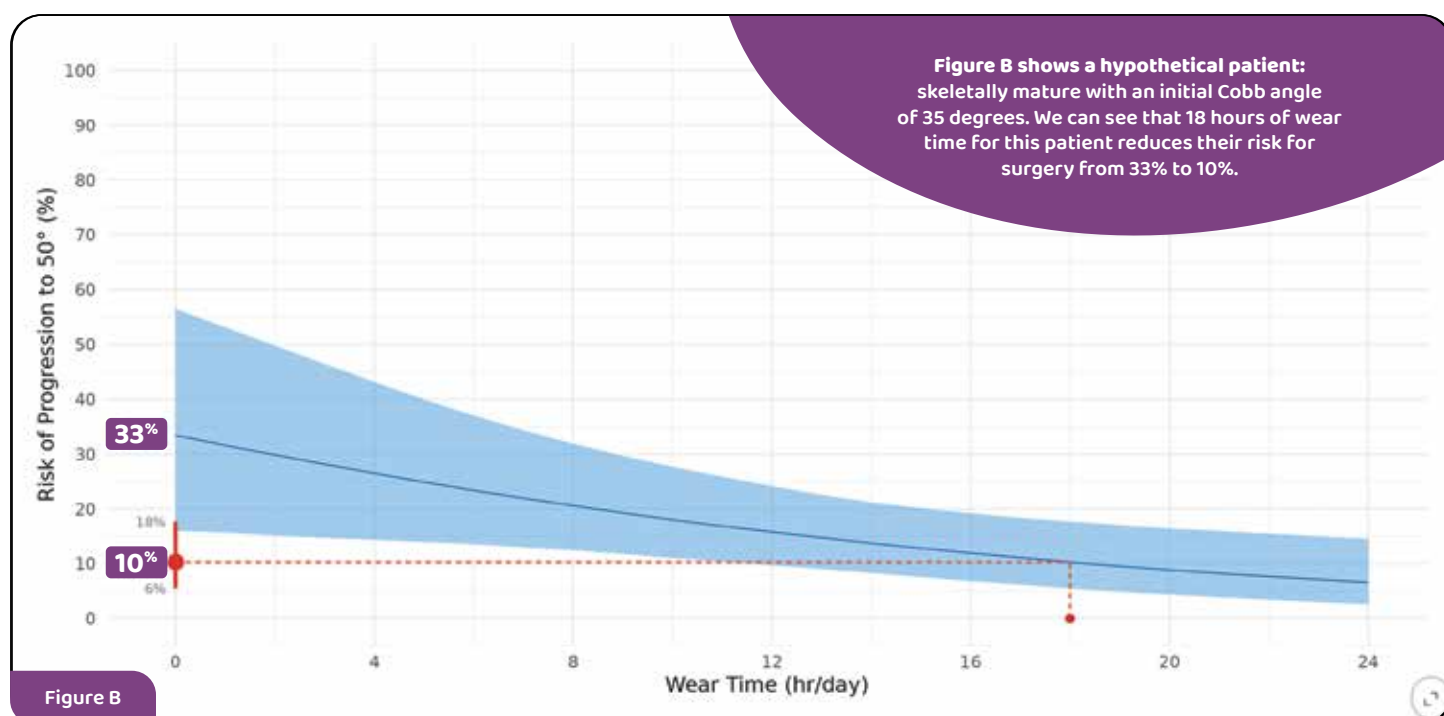
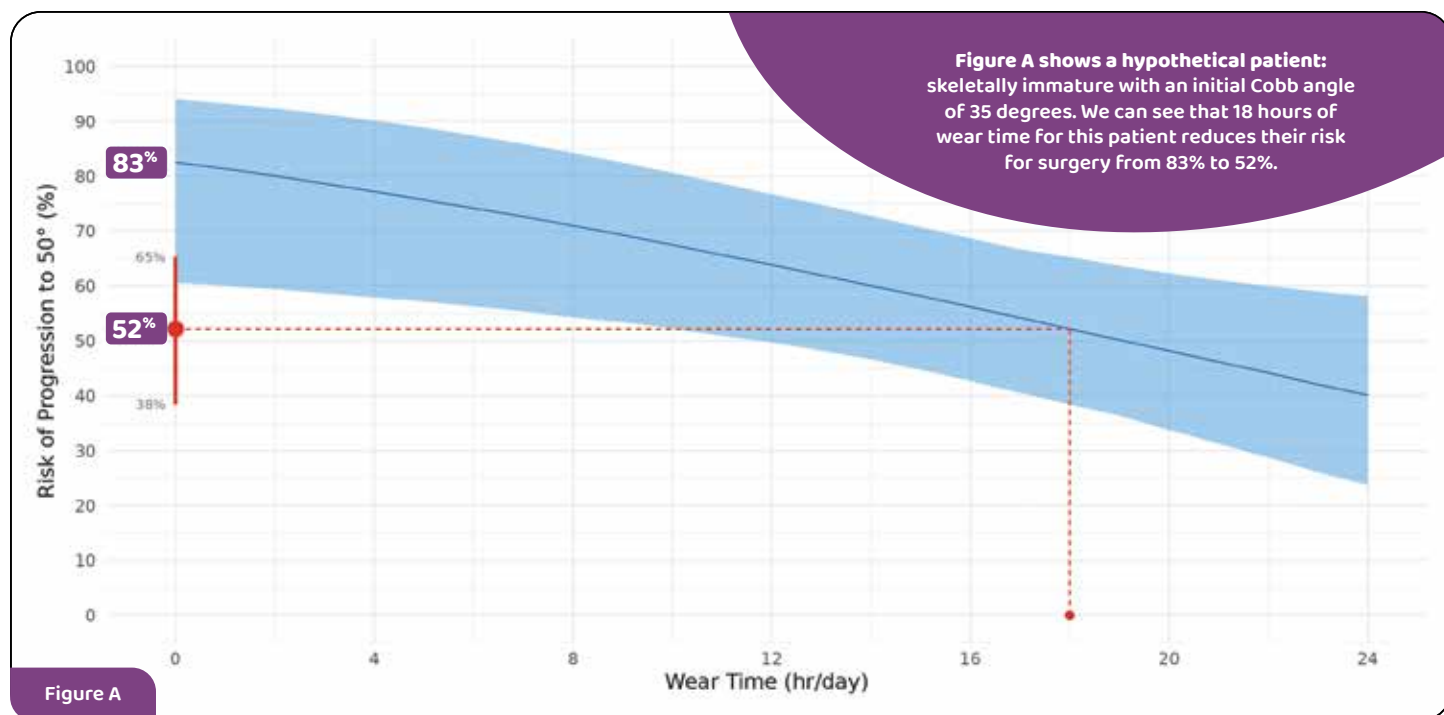


Brian Benish, CO

Comparative Bracing Outcomes

In this sample of two hypothetical patients, we can see the difference in outcome and risk level between a skeletally immature patient and a skeletally mature patient with the same initial Cobb angle.

The module is able to predict the outcome of various wear times, and find the best fit point of wear time vs. lowest risk of surgery. Ultimately, the application allows clinicians to accurately predict what “dosage” of scoliosis bracing will be best for their patients.



Source: Gillette Children's TLSO Treatment Outcomes Estimator Module

Tackling the Transition

Youth with medical complexity report widespread healthcare transition needs

The transition from pediatric to adult healthcare and services is an essential event in the life course of all youth, including youth living with medical complexity. Data from the National Survey of Children's Health indicates that less than 20% of youth receive support for healthcare transition (HCT). Medical and technological advances have significantly increased the life expectancy of children and young adults living with medical complexity (YAMC), so this population is transitioning from pediatric to adult care systems more than ever before.

HCT matters because a successful transition means YAMC can continue their care without a gap, reducing the need for emergent and unplanned care that can impact overall health. Yet barriers to successful HCT for YAMC persist.

To understand the support, tools, and resources that facilitate successful HCT for this population, Gillette Children's recruited three groups of participants to share their lived experiences of "what worked" and "what is needed" for successful healthcare transition.



Wilder Research facilitated all focus group sessions and subsequent content analysis to ensure participants felt safe expressing viewpoints that could be viewed as critical of Gillette services.

The focus groups included:

Group #1:	Group #2:	Group #3:
Young adults aged 24-32 who are their own legal decision-makers and living with cerebral palsy, spina bifida, or muscular dystrophy	Parents of young adults in Group #1	Parents of young adults aged 24-32 who are not their own legal decision-makers and living with cerebral palsy, spina bifida, or muscular dystrophy

The Takeaways

The voices of 10 young adults and 14 parents emerged in three key takeaways under an overarching theme: HCT is an individualized process with success relying on consistent, clearly defined, and system-wide guidelines and resources.

Key Takeaway 1

The lack of system-level capacity (healthcare, insurance, home nursing) resulted in losing resources and support when the individuals moved from pediatric to adult systems. All participants agreed that successful HCT is often guided by individual clinicians and overwhelmingly expressed appreciation for these individuals. However, moving from pediatric/family-centered health systems to adult/patient-centered health systems requires increased self-management, and young adults often felt under-prepared for this role.

Key Takeaway 2

Moving into adulthood is multifaceted and involves changes in healthcare providers and systems, as well as decisions on education, employment, vocational rehabilitation, and where a young adult will live. These transitions occur in different systems, on different timelines, and are often limited by laws on communication and information sharing. Support from formal transition coordinators would improve communication between the multiple health, county/state agencies, and education systems involved during this period.

Key Takeaway 3

Formal peer support programs are needed for young adults with medical complexity and their parents. While participants appreciated Gillette-sponsored social media groups for sharing information and resources, they all agreed that virtual or in-person support groups could provide greater socioemotional and logistical benefits.



Learn more about Gillette's work to make healthcare transition easy for families and providers: gillette.mn/transition-echo

Taken together, these findings should serve as a foundation for organizational and system-level capacity that supports the successful transition of all youth from pediatric to adult care systems.

Making Strides

Gillette experts make progress toward at-home gait analysis

The collaboration of scientists and clinicians is part of Gillette's mission and work to improve the understanding and care of individuals with disabilities and our effort to impact clinical care outside of our hospital walls.

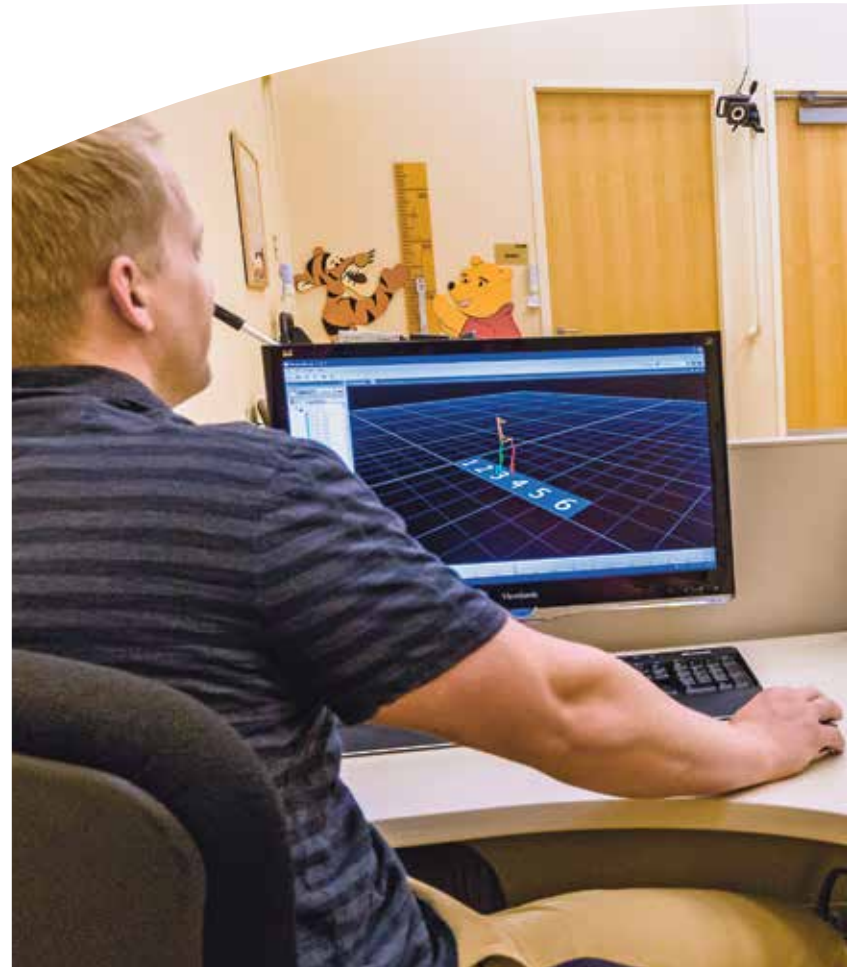
Recent work regarding at-home gait analysis supports these goals. **Andrew Georgiadis, MD**, pediatric orthopedic surgeon, and **Michael Schwartz, PhD**, from the James R. Gage Center for Gait and Motion Analysis research team, have been collaborating for years to make gait analysis more accessible to more families.

Instrumented gait analysis is a time- and labor-intensive process in which human walking is analyzed. The data collected are useful for planning treatment and monitoring the status of patients with gait impairments. However, conducting an instrumented gait test requires space, people, time, and family travel. Additionally, the testing is performed in an artificial environment that may not simulate a patient's real-world walking conditions.

Drs. Georgiadis and Schwartz believe if clinicians and researchers could acquire key gait parameters remotely, that would enable assessments with fewer resources, in the patient's native environment, and with repeated measures. It could also allow for assessments after minor interventions, track recovery after major interventions, and open the door to large-population research and other uses.



Peyton, with sensors attached, walks in the James R. Gage Center for Gait and Motion Analysis to get her gait measured.





Andrew Georgiadis, MD



Michael Schwartz, PhD

"A useful algorithmic analysis of gait videos acquired at home would be easy and quick to use, easily interpretable, and consistent between observations to give users actionable information (minimize bias and variance)," notes Dr. Schwartz.

Dr. Schwartz has collaborated with machine learning researchers at Stanford University to make gait data predictions based on single-camera videos. The proof-of-concept study was published in Nature Communications. He is now working with clinicians at Gillette to test and expand the use of machine learning to predict gait data in patients' home environments.

"Based on a pilot study in 2022-2023, we know that this algorithmic prediction works well enough for large-population research. Now, we want to see if it can be good enough for individual patient decision-making," says Dr. Georgiadis.

Though still early in the two-to-three-year process, Drs. Georgiadis and Schwartz are hopeful that their follow-up investigation is not just successful, but an effort that changes clinical care for families and providers.

Who to Refer for Gait and Motion Analysis

Although people might have similar walking patterns, the way their muscles and joints work together can vary widely. Gait and motion analysis helps to understand and recognize how orthopedic, neurological, and muscular conditions can hinder the movements important for daily living. The innovative video and computer technology at Gillette Children's James R. Gage Center for Gait and Motion Analysis captures movements, muscle activity, and forces that the eye can't see. Information from gait analysis — together with imaging scans, medical history, and the results of other evaluations — helps your care team recommend the best treatments for a wide variety of conditions that disrupt movement.

Who can benefit from gait and motion analysis?

Children and young adults with complex conditions and injuries who have concerns about their walking function and ability are often candidates for gait and movement analysis. Your patient might benefit from a gait assessment if they have:

- Cerebral palsy
- Brain injury and related neurotrauma
- Complex movement disorders
- Conditions that cause toe-walking
- Limb-length discrepancy and limb differences
- Misaligned bones and foot abnormalities
- Spina bifida
- Other neurological or orthopedic conditions
- Amputations

What about movement analysis for upper extremities?

Although gait analysis is primarily used to understand walking problems, the movement analysis technology at Gillette can document the movement and muscle activity of the arms and hands. Your patient may benefit from an upper extremity assessment if they have hand and upper extremity movement problems.

Can a teen get a movement analysis?

Yes, a teen might have motion analysis for the first time because their condition has begun causing pain and stiffness with age. Most often, those who experience difficulty with movement as children need ongoing evaluation and treatment as they transition into teens and adults.



Gait Lab staff monitor and instruct Peyton throughout the analysis.



Watch our "Greats of Gait" video about motion analysis at Gillette.



Danielle Harding, PA-C, helps Jude get comfortable before adjusting his MAGEC rods.

Choosing the Right Specialist

Many teens see adult spine providers when they should be seeing a pediatric spine specialist instead

Pediatricians, family practitioners, and even sports medicine specialists may be the first to observe a young patient's spinal problem. Whether the symptoms are related to pain, stiffness, or misalignment, referring the child or teen to a pediatric spine specialist at Gillette is a helpful recommendation. Pediatric spine expert **Danielle Harding, PA-C**, offers insights on why a pediatric spine specialist is the best option to treat spine conditions in children and teens.

"Gillette's Spine Institute is set up to offer options to patients and their families that take into account a child's developmental stage and growth. A pediatric spine specialist can better assess, manage and treat spine conditions in children because children (and teens) are not simply 'small adults,'" says Harding. "Pediatrics-trained spine specialists have experience monitoring these differences throughout a child's development and can recommend appropriate diagnostic tests and treatments for children and teens, adapting these as the patient grows."

Teens with spine conditions

Managing spine care for teens, who are in a stage of rapid skeletal growth (including growth spurts), requires different

considerations in a treatment plan than would typically be developed for adults with scoliosis, for example.

"Our on-site orthotics team works closely with referring providers to make sure we are offering the best options for spine care management. We also take the teen's psychosocial development into account when developing a care plan," Harding adds. "This is a time when teens might be very active in sports and school activities, and when being different or wearing a brace can cause added challenges." Recent advances, such as nighttime bracing and customizing treatment times through predictive algorithms, provide options that fit best with a teen patient's active lifestyle while still offering exceptional care.

What sets Gillette Children's spine care apart?

Gillette Children's internationally recognized pediatric spine care providers lead the way when it comes to innovating and redefining children's bone and spine surgery and care.

In addition to pediatric neurologists and orthopedists who specialize in spine care, Gillette employs a multidisciplinary team of experts to coordinate everything from X-rays and bracing to occupational and physical therapy. These partnerships mean that all Gillette departments and providers involved in a child or teen's care are aware of progress, concerns, and care decisions.

With many specialties and subspecialties represented under one roof, the Spine Institute can make sure that your patient's care is seamless, as well as attuned to their diverse needs — especially if spine surgery is eventually recommended. We consider how their spine care is integrated with other aspects of their medical care, and take care to maintain ongoing communication with referring physicians and providers. Such consideration is especially important if spine surgery is required, so the patient's entire medical team can ensure that patients and their families are supported medically, mentally, and emotionally.

Common spine conditions in children and teens

- **Pediatric scoliosis:** an abnormal curve in the spine, both idiopathic and associated with an underlying neuromuscular condition
- **Hyperkyphosis:** a larger-than-normal forward curve of the spine
- **Spondylolysis:** a stress injury to the weakest part of the spine
- **Spondylolisthesis:** the forward shifting of one vertebra on another



Refer a spine patient to Gillette at gillettechildrens.org/referral

Treating Cerebral Palsy One 'Robot Test' at a Time

How the Gillette James R. Gage Center for Gait and Motion Analysis helps children who have CP

Kelly Sather says that her 8-year-old son, Owen, calls his gait analysis his "robot test."

"But as parents, we know it is a sophisticated gait and motion analysis that provides helpful information to his team at Gillette Children's," she says.

Gillette's James R. Gage Center for Gait and Motion Analysis is known worldwide for its expertise in diagnosing and planning treatments for people with walking and movement disorders.

Owen had his first gait and motion analysis at Gillette when he was 4 years old. At that time, he thought the sensors placed on his body and the special cameras that captured his movements and muscle activity made him feel like a robot. The name "robot test" stuck.

A Cerebral Palsy diagnosis and plan

"Owen was born as a premie at just 30 weeks," Kelly recalls.

Owen spent the first seven weeks of his life in the neonatal intensive care unit (NICU). When he was just over a year old his doctors in Fosston, Minnesota, referred him to the experts at Gillette, where he was officially diagnosed with cerebral palsy during his first appointment.

"Right away the Gillette doctors started working on a plan for Owen," Kelly says. "We felt reassured and knew Owen was collaborating with a strong team."

Selective Dorsal Rhizotomy (SDR) surgery

When Owen was just over 3 years old, he began to see Gillette physical medicine and rehabilitation physician, **Andrea Paulson, MD**, at the **Gillette Baxter Clinic**, which is closer to his hometown. Dr. Paulson is Gillette's medical director for Greater Minnesota and drives thousands of miles per month to provide care for patients.

"One of the first things Dr. Paulson recommended for Owen was selective dorsal rhizotomy (SDR) surgery," Kelly says.

SDR surgery treats muscle spasticity caused by abnormal communication among the brain, spinal cord, nerves, and muscles. The best candidates for SDR surgery typically have spastic diplegic cerebral palsy that affects the legs more than the arms. This surgery is irreversible and is typically done when a child is 4 to 7 years old.

Gait and motion analysis is an important tool

Owen received a gait and motion analysis to determine if he was a good candidate for the SDR procedure. The test confirmed he would benefit from the surgery. His family is pleased

Owen is Fitted for
new AFOs (Ankle-Foot
Orthosis).

with the results and has noticed improvements to Owen's walking and muscle control.

Kelly advises parents who have a child diagnosed with cerebral palsy to take advantage of the technology, tools, and expert care at Gillette.

"Parents should know a gait analysis makes for a long day," Kelly says. "There are a lot of adjustments and it takes time. I feel the results are so worth it! Owen has now had four gait analysis evaluations and every time it gets easier for him and is less stressful. The insights from the tests are valuable."

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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
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