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JOURNAL

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RESEARCH:

New Treatment Can Help Spinal Muscular Atrophy Patients

See how it's helping Rose and Xavier Menke, who both have the rare disease

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On the cover: Xavier Menke and his sister, Rose, wait for their neuromuscular neurology appointment at Gillette Children's.

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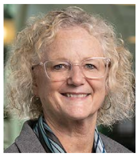
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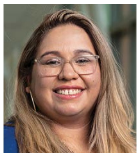
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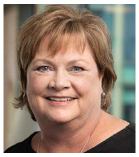
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Meet the Providers in this Issue

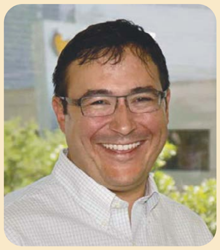
Two Gillette Neurologists Share a Passion for Helping Patients Who Have a Rare Disease

Pediatric neurologists specializing in neuromuscular disorders, **Randal Richardson, MD**, and **Jamie Eskuri, MD**, say guiding families through a rare disease diagnosis is one of the most rewarding parts of their jobs. The search for answers and treatments can be exhausting, but Dr. Eskuri and Dr. Richardson are proud that Gillette can help light a path and be a guide for families.

"Academically, my job is interesting," Dr. Eskuri says. "But the more fulfilling part of the work we do in neurology is the emotional and social help we can provide parents and children."

Dr. Richardson agrees. "When you have a child with a rare condition, you're going through the 'diagnostic odyssey,'" he says. "It's frustrating to not know what the future holds. We don't have a crystal ball, but we can provide knowledge and input gleaned from collective years of experience caring for other children who have a similar condition."

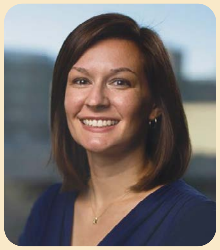
Read more about neuromuscular neurology care at Gillette on page 8.



Randal Richardson, MD

Pediatric Neurologist

Education & Training
Medical School: Brown University Alpert Medical School, Providence, Rhode Island
Graduate Degree: Master's of Medical Science in Neurophysiology
Fellowship: Neuromuscular Disease and Electrodiagnostic Medicine, University of Washington and Seattle Children's Hospital
Board Certification(s): Adult and Child Neurology, Neuromuscular Medicine
Career Highlight: "I openly tell people that helping to develop SMA treatments is probably the most important project of my life," Dr. Richardson says.



Jamie Eskuri, MD

Pediatric Neurologist

Education & Training
Medical School: University of Iowa Carver College of Medicine, Iowa City, Iowa
Residency: Boston Combined Residency Program in Pediatrics, Boston Children's Hospital and Boston Medical Center, Boston
Fellowship: Neuromuscular Medicine Clinical Fellowship, Beth Israel Deaconess Medical Center
Board Certification(s): Neurology with Special Qualifications in Child Neurology
Career Highlight: "Many of the kids I see have genetic conditions or other things that means they're impacted by their condition for a long time—maybe their entire lives," Dr. Eskuri says. "Getting to know these kids and their family members, and to see them in many circumstances multiple times a year, I love that. I've been endlessly struck by the resilience of Gillette kids and their families."

New Treatment for Sleep Apnea with Down Syndrome

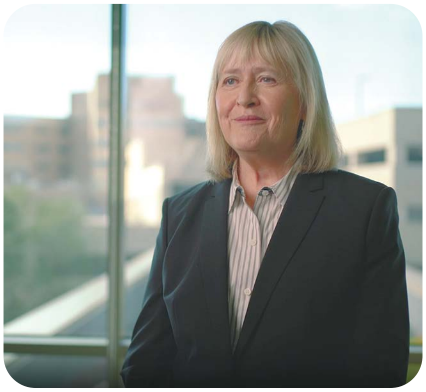
Gillette is taking steps to help teens who have Down syndrome and Obstructive Sleep Apnea (OSA) sleep better at night. Gillette is the first and only healthcare facility in the Twin Cities metro area to offer the Inspire Implant to improve quality of life for Down syndrome pediatric patients aged 13 and older.

One of the current treatments for people with obstructive sleep apnea, a continuous positive air pressure (CPAP) mask, may not be ideal for people who have Down syndrome. That's because the CPAP mask requires people to wear it over the nose so it can provide a puff of air into the throat, relieving obstructions so the airway won't collapse.

Gillette Children's sleep medicine specialist, **John Garcia, MD**, and his team can help children who have Down syndrome get better rest. "People who have Down syndrome simply do not adhere to CPAP as well," Dr. Garcia says. "The Food and Drug Administration (FDA) has recently authorized the hypoglossal nerve stimulator, the Inspire Implant, for persons with Down syndrome as young as 13 years old." Patients at Gillette began receiving this new treatment in the fall of 2023.

According to the **National Institutes of Health**, hypoglossal nerve stimulation (HGNS) is a sleep apnea treatment involving an implanted medical device that works by stimulating the hypoglossal nerve in a rhythm synchronized with the patient's breathing. This stimulation helps to keep the person's airway clear during sleep.

People who have Down syndrome often have decreased muscle tone in the genioglossus muscle, one of several muscles stimulated by the hypoglossal nerve. This results in the tongue retracting back into the throat during sleep and obstructing the airway and this can reduce oxygen levels in the body.



Quanbeck Appointed Associate Chief Medical Officer

Deborah Quanbeck, MD, will take on the role of Associate Chief Medical Officer at Gillette Children's. Dr. Quanbeck will support physicians in elected or appointed positions within the medical staff. Her focus will be on maximizing the effectiveness of their services in these roles and overseeing Graduate Medical Education and Continuing Medical Education. She was the Director of Medical Education for the Orthopedic Residency Program from 2002 to 2020 and took on the Director of Graduate Medical Education at Gillette in 2020.

Dr. Quanbeck will also continue her work as an orthopedic surgeon. She is a seasoned surgeon and leader known for instilling trust, driving results, ensuring accountability, and advancing administrative work. Her extensive expertise in orthopedics and graduate medical education is well recognized at Gillette.

In addition to her leadership at Gillette, Dr. Quanbeck has held various leadership roles, including Chief of Staff, Chairperson for the Surgery Committee, and Chairperson for the Quality and Safety Council. Externally, she has served as the president of the Twin Cities and Minnesota Orthopedic Societies and as a Board member of the Pediatric Orthopedic Society of North America.

FEATURE

Can We Predict Pain?

A new study aims to understand postoperative pain in children who have cerebral palsy

To better understand postoperative pain and surgical outcomes in children who have cerebral palsy (CP), Gillette Children's has launched the groundbreaking multisite Predictors of Pain research study.

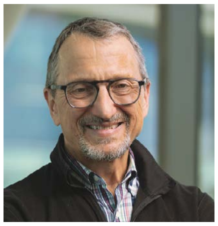
Funded by an R01 NIH grant—Gillette's first primary R01 award—this study is led by Senior Clinical Scientist **Chantel Burkitt, PhD**, along with **Liz Boyer, PhD**, and **Tom Novacheck, MD**, orthopedic surgeon and Chair of Gillette Children's Cerebral Palsy Institute. This study is conducted at Gillette as well as Nemours Children's Hospital in Delaware. The Nemours site is led by M. Wade Shrader, MD, orthopedic surgeon and current President of the American Academy for Cerebral Palsy and Developmental Medicine (AACPDM), along with Jason Howard, MD.

The Predictors of Pain study will identify predictive factors for the development of chronic postoperative pain. To do this, the study will engage 500 families over five years, focusing on children aged 5-17 who have a CP diagnosis and who are undergoing single-event, multi-level surgery or spine surgeries. The study will document the typical trajectory of perioperative and postoperative pain experience in children with CP and examine pain intensity, frequency, duration, and interference as well as sensory, physical, and emotional factors.

How Can We Measure Pain?

To ensure their data points are comprehensive, the research team will rely on online survey responses over 13 months as well as objective measures of pain collected during sensory testing, opioid use, and data collected in Gillette's Gait & Motion Analysis Lab. Gait lab data will be essential to learning whether or not a participant's pain affects their ability to achieve gait and mobility outcomes.

Chantel Burkitt, PhD



Tom Novacheck, MD

Liz Boyer, PhD

How Sensory Testing Helps Measure Pain

Sensory testing might be the easiest test you'll ever take, because our bodies react to tactile stimulation—and pain—involuntarily. The sensory testing used in this study is especially useful for research involving some patient populations at Gillette Children's, which can include individuals who have cognitive delays or are nonverbal.

Chantel Burkitt, PhD, and her pain research team at Gillette and the University of Minnesota have spent the last decade, in part, validating their sensory testing as a reliable way to measure and characterize pain. "Essentially, sensory testing helps us understand how a person's peripheral nerve fibers are working by evaluating a person's sensitivity to tactile stimulation."

The test includes a few different parameters, but from start to finish, the test takes less than five minutes.

- Light touch with a thin von Frey filament
- Light pin prick, like those used by neurologists to test for diabetic neuropathy
- Cool touch at room temperature
- Warm touch at 41 degrees Celsius
- Pressure touch at four pounds of pressure
- Repeated touch with a thicker von Frey filament 30 times for 30 seconds

"The repeated touch is an especially interesting component, as that is really designed to get at pain of the central nervous system. It's one of the best predictors of pain outcomes that we've found," Dr. Burkitt says. "The idea is that if someone is living with chronic pain, their nervous system is already constantly aggravated. That 30th touch is going to be more sensitive in those cases than the first few touches. Occasionally, we see patients who are so sensitive to the test that we terminate the test before we can get through all 30 touches. But even that is very useful information."

Each sensory test is video recorded and subsequently coded by researchers who are specifically trained to look for signs of facial reactivity, like a furrowed brow or grimace, changes in the shape of the mouth and lips, changes in vocalizations, as well as flinches and other bodily reactions. A three-minute video can take more than two hours to code properly.

Watch a video of a sensory test at gillette.mn/sensory-test

> *Chronic postoperative pain is defined as 1) new pain that starts after surgery OR pre-existing pain that worsens after surgery and 2) remains present at least three months after surgery.*

Dr. Burkitt believes one of the most important pieces of the study is the preoperative parent questionnaire. She says, "The parent responses will give researchers a baseline understanding of a patient's pain to which they can compare all future data points."

Dr. Novacheck believes the surveys will make all the difference to understanding how much pain his patients are experiencing. He explains, "It's a well-documented phenomenon that people don't always completely report their pain to their doctor, especially one where there's an ongoing relationship. I expect I will hear about more pain from these patient and family surveys than what I hear about in clinic."

Connecting Pain and Surgical Outcomes

The questionnaires will continue throughout the patient's surgical journey, creating a clear map of the pain trajectory in each child. Dr. Burkitt says, "Once we've done that, the next aim is to see how well we can predict pain outcomes and surgical outcomes based on the data collected."

Dr. Novacheck notes that how pain relates to orthopedic outcomes has been a known issue for a long time. "If I or one of my colleagues recommends orthopedic surgery with pain relief as one of the goals, there is nothing in the body at the time of the surgery that you can look at that says, 'Here! I'm the pain, take me out,'" Dr. Novacheck says. "So as a clinician, when you are considering the patient history, the exam findings, the patient's goals, and the data from this research, we want to be able to confidently characterize the pain and recommend a surgery that has a greater chance to help."

Researchers collect saliva to objectively measure biomarkers of pain in nonverbal patients.

Turning Predictions into Care Guidelines

It will take time, but once the final data is evaluated, Dr. Burkitt is dreaming big about the potential uses for the study. "I'm hoping this study will give us strong, evidence-based care guidelines," she says. "Let's say we see a patient rating their pain a 6 out of 10 before surgery. We hope we'll be able to confidently say to families that postponing surgery so we can work toward managing their pain to be a consistent 3 out of 10, then might mean they'll have a stellar surgical outcome and will be more likely to meet all their postoperative goals."

While mitigating the risk factors for ongoing postoperative pain is a priority, looking even further into the future of this research, Dr. Novacheck says, "Ideally, after making those changes to our preoperative care guidelines, we can repeat this study in five, 10, 15 years and see that, yes, there is a lower percentage of patients having significant pain and pain that interferes with their function is less likely."

Enrollment for the Predictors of Pain study is ongoing at both Gillette Children's and Nemours. The study is expected to be fully enrolled by Summer 2027.

> *"Ideally, after making those changes to our preoperative care guidelines, we can repeat this study in five years, 10 years, 15 years and see that yes, there is a lower percentage of patients having significant pain and pain that interferes with their function is less likely."*
>
> *–Tom Novacheck, MD*

Why research pain in children who have CP?

"There's been a big burst in pain research, especially for typically developing kids, but there's a lot less attention paid to kids with disabilities," Dr. Burkitt says. "After 15 years at Gillette asking patients about their pain, I've always felt like our patients have more pain than typically developing children, especially our patients with cerebral palsy."

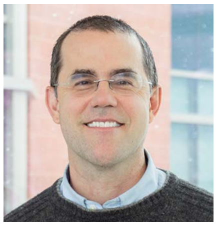
"Taking full responsibility for your patients' well-being is a key aspect of being an institute. Developing treatments and conducting research like this is an essential part of that," Dr. Novacheck says.

With the Cerebral Palsy Institute supporting and disseminating conclusions from this research, the clinical teams at Gillette will be able to implement changes at the bedside much faster and take concrete steps to help manage pain for all patients with CP, even those outside the walls of Gillette Children's.

Learn more about Gillette Children's Cerebral Palsy Institute.

Sleep Help for Children and Teens with Down Syndrome

Does your child need a sleep evaluation?


John Garcia, MD

The Gillette Children's Sleep Health Clinic wants families of children who have Down syndrome to know they have resources to help with sleep concerns.

"There are two areas of stress that families are dealing with when it comes to good sleep and Down syndrome," Gillette sleep medicine specialist, **John Garcia, MD**, says. "The first is obstructive sleep apnea and the second is insomnia. Our expert sleep medicine team can help with both and provide care for other sleep concerns."

Read more about the new sleep apnea treatment offered at Gillette on page 3.

Dr. Garcia reports that many people who have Down syndrome often have issues with insomnia, including more fragmented sleep and frequent awakenings compared to typically developing children. Dr. Garcia says it's important for families to know that there is help to improve sleep and to make sure children can be as well-rested as possible.

"We have old and new medications that can help with insomnia," Dr. Garcia says. "Tried and true medications like trazodone, doxepin, clonidine, and hydroxyzine are often effective. Survorexant may help with insomnia. Children with all types of developmental disabilities have the most difficulty staying asleep, they wake up in the middle of the night."

The first step for families struggling with sleep issues is to talk to a sleep doctor who can help decide whether a medication, a sleep study, or other therapies are indicated.

"When a parent notices their child chronically working harder to breathe, having breathing pauses, snoring persistently, waking more frequently for unexplained reasons, or sleeping more during the day, that's a sign that this child should have their sleep evaluated," Dr. Garcia suggests.

Gillette Has The "Gold Standard" In Sleep Programs

The American Academy of Sleep Medicine (AASM) reports the Gillette Children's Sleep Health Clinic is one of the most well-run sleep labs its surveyor has ever reviewed. The AASM awarded Gillette a five-year re-accreditation demonstrating Gillette's commitment to high quality, patient-centered care. Gillette has one of the nation's only sleep medicine programs specifically designed for people who have disabilities or other complex health conditions.

Dr. Garcia says this special patient population makes Gillette different from other sleep clinics. "Simply put, our staff has to work harder and care more tenderly. Children with developmental disabilities pull off their electrographic sleep leads more frequently, are at more risk for falls, and have a variety of unpredictable behaviors," Dr. Garcia says. "You name a stressor and the Gillette sleep techs have encountered it."

Read more about Sleep Medicine services at Gillette.

Gillette Children's offers comprehensive treatments for children who have Down syndrome and sleep concerns. Gillette is the first and only healthcare facility in the Twin Cities metro area offering the Inspire Implant to improve quality of life for Down syndrome pediatric patients ages 13 and older.

Gillette Pioneers New Breakthroughs in Spinal Muscular Atrophy Treatments

Meet Xavier and Rose Menke

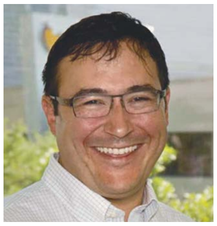
Gillette pediatric neuromuscular neurologist, Randal Richardson, MD, MMS, is a leading SMA researcher and provides the latest in SMA treatments and support to patients like Xavier Menke.

Xavier and Rose Menke are part of a new generation of children diagnosed with spinal muscular atrophy (SMA) who have a brighter future thanks to new treatment breakthroughs.

The neurology team at Gillette Children's is one of the leading pediatric facilities involved in SMA drug trials and neuromuscular disease research and treatment.

Research, done in part at Gillette, is now providing more positive outcomes for children diagnosed with this rare, hereditary, and often-fatal disease affecting muscle strength and movement. In the past, children diagnosed with the most common type of SMA (type 1) had a lifespan of less than two years without treatment.

Gillette pediatric neuromuscular neurologist, Randal Richardson, MD, MMS, is a leading SMA researcher and has been on the forefront of developing these new treatments.



Randal Richardson, MD, MMS

Parents Appreciate the Gillette SMA Care Team

For the past six years, parents Carrie and Tony Menke have been making the four-hour drive from Sioux Falls, South Dakota, to see Dr. Richardson and his neurology team.

"We just love Dr. Richardson," Carrie says. "He's been wonderful for Xavier, who is 10, and he's cared for our now 3-year-old daughter, Rose, even before she was born. We totally feel it's worth the extra effort to come to Gillette in St. Paul for their treatment."

Hope For a New Generation of SMA Patients

Dr. Richardson and his team were key contributors in the 2016 EMBRACE clinical trial that led the Food and Drug Administration (FDA) to approve Spinraza® (nusinersen) for SMA treatment.

Spinraza is hailed as the first real treatment for SMA. It works by targeting the SMN2 gene, causing it to make a more complete protein. According to Cure SMA, once a patient receives four loading doses within the first two months of treatment, they receive a maintenance dose every four months for life.

Gillette and Spinraza Help Xavier

The approval of Spinraza came at just the right time for Xavier Menke, who was born in November 2013.

"Xavier was officially diagnosed with SMA in 2017," Carrie says. "It was just a few months after the first SMA treatment became available."

His parents report Xavier was born healthy, but they started noticing symptoms when he was around 2 years old.

"Something was off," Carrie says. "He had been toddling around and talking from an early age. He walked at 1 and was right on track. Then when he was about 2, he would often fall and using the stairs became a challenge. He started to decline rapidly."

As Xavier's symptoms became more severe, the Menkes sought advice from their family pediatrician who recommended that Xavier go to Gillette for an evaluation.

Gillette Experts Make a Difference in Treatments

Xavier initially received the four loading doses of Spinraza and he comes to Gillette several times a year, during which Dr. Richardson monitors him and gives him lumbar punctures of the medication.

"Nusinersen (Spinraza) represents the first real opportunity to shift the focus in neuromuscular care from diagnostics and symptom-focused treatments to true medical treatment for a previously untreatable genetic disease," Dr. Richardson says.

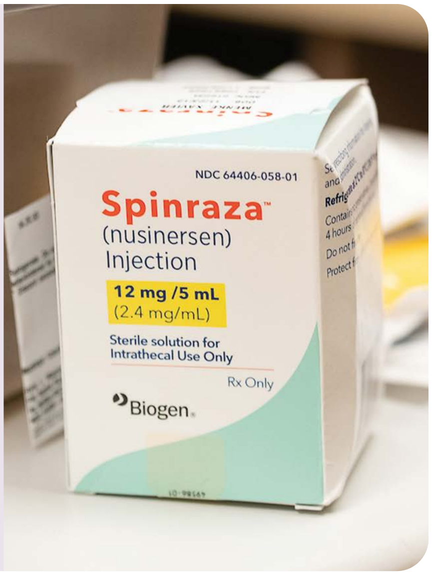
"Embracing this early and aggressively meant that I peddled a bit in hope, a word we should use more commonly in medicine," Dr. Richardson says. "Once the new natural history of nusinersen-treated SMA became established…it turned out that our hopes were indeed congruent with reality. Xavier proved to me that it is OK to hope and strive for a better tomorrow."

SMA Treatments Come With a Price

The new SMA treatments come with a price—literally. According to *The New York Times*, Zolgensma's list price in the United States in 2019 was $2.1 million. The January 2023 article states Zolgensma is approved for use in 46 countries and has been given to more than 2,500 children. Governments, insurance companies, and parents continue to work on ways to make this treatment affordable and possible for children.

Another *New York Times* article states the price of Spinraza is about $125,000 per dose. Patients initially need to have four loading doses and take three or four doses each year for the rest of their lives.

Dr. Richardson and the Gillette team continue to work to help Gillette patients navigate the insurance issues involved in getting coverage for the SMA treatments. Gillette has no involvement in, or influence over the price drug companies set for Spinraza, Zolgensma, or any other SMA drug treatment. It's important to note, both Zolgensma and Spinraza are treatment options for some, but not all, SMA patients.



Gillette and Zolgensma Help Rose

Xavier's sister, Rose, is part of a new generation of children diagnosed with SMA.

Before she was born, Rose was tested in utero to detect if she had SMA. The amniocentesis test came back positive for SMA, and a neonatologist was present at Rose's birth on Dec. 8, 2019.

"A week after Rose was born, we traveled to Gillette to see Dr. Richardson," Carrie says.

When she was just one month old, Rose received the second SMA treatment approved by the FDA. Dr. Richardson and his team administered Zolgensma, which is the first gene therapy approved to treat neuromuscular disease.

The FDA approved Zolgensma in May of 2019. According to the Cure SMA website, Zolgensma is given through an intravenous (IV) infusion that takes about one hour. It is a one-time treatment to treat children with SMA who are younger than 2 years of age.

So far, Rose shows no sign of the symptoms associated with SMA. She walks, runs, jumps, and is a ball of positive energy. Unlike her older brother, Xavier, Rose does not need continued lumbar punctures or as many visits to Gillette.

Dr. Richardson says Xavier and Rose are examples of how important it is for children to be diagnosed as early as possible. The Menke children also highlight the progress in SMA care.

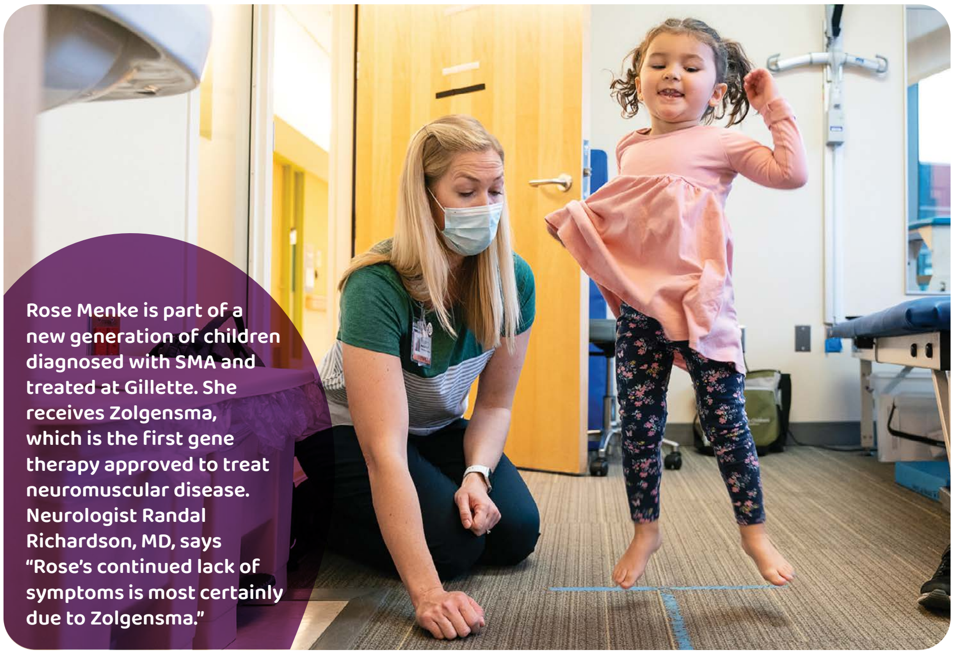
"Rose's continued lack of symptoms is most certainly due to Zolgensma," Dr. Richardson says.

Gillette Helps to Ensure SMA Newborn Screenings

Thanks to the work of Dr. Richardson and his team, in March 2018 Gillette was instrumental in ensuring children born in Minnesota are screened for SMA at birth. Because of this, Minnesota was among the first states in the country to screen for SMA. This is important because the sooner a child is diagnosed and treated, the less damage there is from SMA.

Gillette is in the Cure SMA Care Center Network and is active in maintaining and enhancing the Cure SMA Clinical Data Registry, which is hoped to evolve to maximize both medical and supportive therapies for SMA.

Children like Xavier and Rose Menke are examples of how Gillette's focus on research and its unwavering commitment to cutting edge care can have an impact on a child's life.



Rose Menke is part of a new generation of children diagnosed with SMA and treated at Gillette. She receives Zolgensma, which is the first gene therapy approved to treat neuromuscular disease. Neurologist Randal Richardson, MD, says "Rose's continued lack of symptoms is most certainly due to Zolgensma."

To make an appointment with the Gillette Neurology department please call **651-401-7328** or to refer a patient call **651-325-2200**.

What Influences Parent Decision-Making?

Making decisions about a child with CP can be complex. New research explores parents' lived experience.

The path of a child living with cerebral palsy (CP) is filled with emotions, obstacles, and decisions. Gillette Children's researched what influences parental decision-making to offer enhanced support to parents.

The Complexity of Decision-Making with a Young Child with Cerebral Palsy: Understanding Mothers' Lived Experiences Using a Phenomenological Approach was shared at the American Academy for Cerebral Palsy and Development Medicine (AACPDDM) and was awarded the conference "Top 10" out of 120 papers submitted.

The study was conducted with 18 mothers by Gillette experts **Meghan Munger, PhD, MPH**, **Rhonda Cady, PhD, RN**, and **Tom Novacheck, MD**, as well as their colleagues outside of Gillette, Timothy Beebe, PhD, Nathan Shippee, PhD, and Beth Virnig, PhD, MPH.

The team identified five themes influencing how and why families make health-related decisions for a child with cerebral palsy. Complex and dynamic experiences influence goals, priorities, and how to seek health services.

1. Evolving Expectations

Expectations regarding their child's diagnosis, prognosis, and abilities evolve. Frequently, caregivers find themselves adjusting and reshaping goals and priorities. This change may differ for each caregiver, even within the same household.

> *"We knew from the start there was going to be an issue…I have friends who didn't find out until 2 [years of age]. They didn't know there was an issue and their child's going to be complex. And they spent kind of the whole next year reeling from that…that wasn't my experience. I knew from 22 weeks **and had two years to process that** [before he was diagnosed]."*
>
> *– Patient Mother*

> *"I'm not trying to fix her or cure her…I'm the only one, of the people that helps me with her the most, my grandmother and her dad; I'm the only one that is OK with where she's at and where she might be in the future. They're still at the 'gotta fix the problem' stage."*
>
> *– Patient Mother*

2. Quality of Life for the Child

Decision-making includes a balance of social and emotional well-being, and sometimes comes at the expense of a known benefit. In addition, as a child gains agency, their voice becomes more vital and influences the expectations.

> *"I tend to be more what do my kids like and want versus where do we get the most progress, where are we going to get those academic achievements, what's going to get her on the fastest pace to be able to kick a ball, like all of that kind of stuff. I feel like I want to do all of that, but I want her just to be a kid who just gets to play at the pool with her siblings—**I just want her to be a kid with her siblings and not be the kid with disabilities**, and so I have tried to manage and balance that."*
>
> *– Patient Mother*

3. Family Well-being

What might be considered best for the child might not be suitable for the family. Caring for a child with CP often becomes a balancing act in context with the family's well-being. Financial considerations, marriage dynamics, and overall family well-being are interwoven into decision-making.

"It's been overwhelming at times, thinking about another appointment. We have a bit of a balancing game—is it worth the drive and all the investment for some appointments? Sometimes we've been like, not right now, we're good. Part of it is what's going on with our family...We have to weigh that. ***Sometimes, we have to say that appointment is not as important as we think.*** *It might be important for her, but then for everyone else, it's actually detrimental."*

– Patient Mother

4. Uncertainty

Parents must weigh multiple known and unknown factors for each decision while not knowing what the future holds.

"You don't want to put your child through surgery...It's all those 'what ifs', and she already fought her little heart out to be alive. ***What if I make their decision, as a parent, to put her through this? But what if we didn't? What if we didn't?"***

– Patient Mother

"Each of these specialists is watching one specific area, but who is looking at her globally? That isn't me, right? Because I don't know what I'm doing...I really wish that there was somebody who could just help us manage it all... at that global level... ***We can't be proactive because we don't know until it becomes a problem****...Then again it becomes this thing like,* ***well I'm just trying to survive, every day, so I don't have time to be looking into other stuff all the time."***

– Patient Mother

5. Overburden

It includes countless administrative tasks like scheduling appointments, navigating state services, or insurance approvals. This is further complicated by inconsistent guidance from professionals.

"We were told as we left the NICU that we are eligible for county insurance. ***As a well-educated English speaker with consistent access to a phone and computer, I found that process so frustrating.*** *I started it four different times and gave up. I didn't get her signed up until she got the actual CP diagnosis and then it was even a year and a half later because it was such a mess."*

– Patient Mother

"Insurance is definitely a headache. I'm already struggling with a lot and then having to answer...I know it's kind of going to sound crazy, but ***for something to get approved you have to explain the very worst scenario for your child*** *for them to be able to approve something that your child needs.* ***Otherwise, the first thing they will say is no."***

– Patient Mother

Navigating these complexities requires a multidisciplinary team that provides guidance and support. Gillette Children's Cerebral Palsy Institute advocates for a child's total wellness. Scan the QR code to read more about the Institute.

WINTER 2024

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Partners in Care
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**

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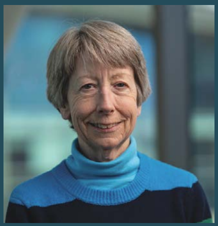
Transforming Pediatric to Adult Healthcare Transition in Minnesota

Education Available Now

The Health Care Transition Learning Collaborative is a partnership between Gillette Children's and Got Transition, a program of the National Alliance to Advance Adolescent Health. Gillette Children's **Tori Bahr, MD**, Internal Medicine and Pediatric Physician Medical Director of Pediatrics, and **Rhonda Cady, PhD**, Clinical Scientist and Health Services Research Program Lead, co-lead the collaborative.

The collaborative seeks to bring together a multidisciplinary group for monthly learning sessions. The sessions utilize the Project ECHO learning model, an "all teach, all learn" approach and offer CME credit. Each 60-minute session includes a didactic discussion around a session-specific topic, followed by a case presentation and case discussion.


Tori Bahr, MD


Rhonda Cady, PhD

Register or view previous session recordings at:
Gillette.mn/transition-echo.

Next Session Topic: Transfer & Integration into an Adult Outpatient Practice

Monday, February 12, 2024
12:15 p.m. - 1:15 p.m.

After attending this session, participants should be able to:

- Outline goals and action steps to ensure a safe transfer from pediatric to adult outpatient care for young adults including finding an adult provider, creating welcome and orientation materials, planning initial visits, and reducing no-show rates.
- Identify challenges in ensuring a safe transfer (lack of information, warm hand offs, and lost to follow up).
- Implement tools that can help improve transfer and integration into adult care.