Gillette
Partners in Care
JOURNAL

WINTER 2023

FOCUS:

World Class Rare Disease Care at Gillette

Breakthroughs in treatments, medications, and therapies **PAGE 6**

gillette CHILDREN'S | 125 YEARS

Gillette Partners in Care JOURNAL

On the cover: Gillette Complex Care Pediatrician Art Beisang, MD, and Pediatric Neurologist Tim Feyma, MD, see a patient during their monthly multidisciplinary clinic focusing on Rett syndrome.

About Our Journal
Partners in Care is produced by the Marketing and Communications team in collaboration with our Provider Relations team. Issues are published quarterly. To subscribe to our monthly e-newsletter, visit **gillette.mn/pic.**

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Colleagues,

As we celebrate the new year, I'd like to thank you for your continued support of our mission, your partnership, and your trust in the care of your patients.

In 2023, Gillette Children's remains focused on what we do best—pursuing treatments, medications, and therapies to improve the lives of individuals with brain, bone, or movement conditions. In this issue, you'll learn about our work to become a beacon of hope for patients who have rare diseases by putting research and treatment development at the forefront of our efforts.

You'll also read about important foundational research in muscle quality. With a new grant, our research team will be able to provide baseline data of different muscle characteristics for larger longitudinal studies comparing post-intervention muscle quality.

With these goals in mind and many more, we look forward to working with you to make the new year bright with health and opportunities for our patients.

Gillette Celebrates Two Retirements

Pediatric craniofacial and plastic surgery physician, **Martin Lacey, MD,** and pediatric orthopedic surgeon **Stephen Sundberg, MD**, retired this winter.


Martin Lacey, MD

Dr. Lacey joined Gillette in 2008 and has served in various roles, including leading the Pediatric Craniofacial and Plastic Surgery Department. He personally recruited his colleague, **Jo Barta, MD**, to join the Gillette craniofacial and plastic surgery team in 2019.

"I've known Jo since her time at medical school, and I was a mentor to her. She's now my colleague and is a huge asset to the department," Dr. Lacey says. "**Dr. Courtney Carpenter** recently joined the team and has already connected with patients and families. I know our craniofacial and plastic surgery patients are in great hands with these two doctors."


Stephen Sundberg, MD

Dr. Sundberg has been with Gillette for more than 30 years and has served in various roles, including leading the Orthopedics Department.

"I've been blessed to be at Gillette during a phase of phenomenal growth," Dr. Sundberg says. "When I started, Gillette was doing 500 surgeries a year—now we're doing nearly 10 times that. When I started, we had one location that provided orthopedic care—now, we've expanded our specialties and geography to reach and help so many more kids."

Gillette Children's will ensure your patients continue to receive the best possible care with the help of our expert, collaborative teams. Drs. Lacey and Sundberg agree—it's been an honor to partner with you in the care of your Gillette patients.

If you have a patient requiring immediate or short-term care for a craniofacial, plastic surgery, or orthopedic issue, please call **651-325-2200** or visit **gillettechildrens.org/refer**.

Growing Team of Physicians Adds Expertise

Gillette has recently welcomed new providers across many specialties, and they are actively accepting new patients. Get to know our new team members!

Courtney Carpenter, MD, joined the Craniofacial team at Gillette. She has been board certified by the American Board of Plastic Surgery since 2017.

Charbel El Kosseifi, MD, joined the Gillette Neurology team, specializing in epilepsy and seizure care.

Alison Dittmer, MD, joined the Orthopedics team. Dr. Dittmer specializes in adolescent hip dysplasia, hip impingement (femoral acetabular impingement), and slipped capital femoral epiphysis.

Kyle Miller, MD, joined the Gillette Orthopedics team. He specializes in scoliosis, neuromuscular disorders, and lower extremity alignment concerns.

Nick Nahm, MD, joined the Gillette Orthopedics team. Dr. Nahm specializes in limb length discrepancies and limb differences, myelomeningocele, and cerebral palsy.

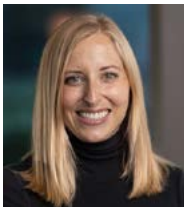
Emmalynn Sigrist, DO, joined the Gillette Orthopedics team. She specializes in limb reconstruction, trauma, fractures, and hip dysplasia.

Natalie Stork, MD, FAAP, joined the Gillette Orthopedics team. Stork specializes in the nonoperative treatment of orthopedic conditions and sports medicine.

To refer a patient to one of our new providers, call **855-325-2200** (toll-free) or refer online at **gillettechildrens.org/referral**.


Courtney Carpenter, MD


Charbel El Kosseifi, MD


Alison Dittmer, MD


Kyle Miller, MD


Nick Nahm, MD


Emmalynn Sigrist, DO


Natalie Stork, MD, FAAP

Kevin Walker, MD, Takes on Lead Surgical Services Role

Orthopedic surgeon **Kevin Walker, MD**, took on a new role at Gillette Children's last fall as the medical director of Surgical Services. Dr. Walker transitioned into the role after Peter Kim, MD, served most recently.

Dr. Walker joined Gillette in 1997. He is a member of the Pediatric Orthopaedic Society of North America, the American Academy for Cerebral Palsy and Developmental Medicine, and the American Academy of Orthopaedic Surgeons. He specializes in lower extremity alignment concerns and other orthopedic conditions.

Neurosurgery Team Offers Expertise, From Simple to Complex

The Gillette Neurosurgery team is proficient in diagnosing and treating a wide array of conditions

With the largest group of pediatric neurosurgeons in Minnesota, the Gillette Neurosurgery team takes on the full scope of conditions and concerns affecting the spinal cord, neck, nerves, and brain. The team also provides neurosurgical care to treat the secondary effects of complex conditions.

Patrick Graupman, MD
Neurosurgeon

Peter Kim, MD
Neurosurgeon

Debbie Song, MD
Neurosurgeon

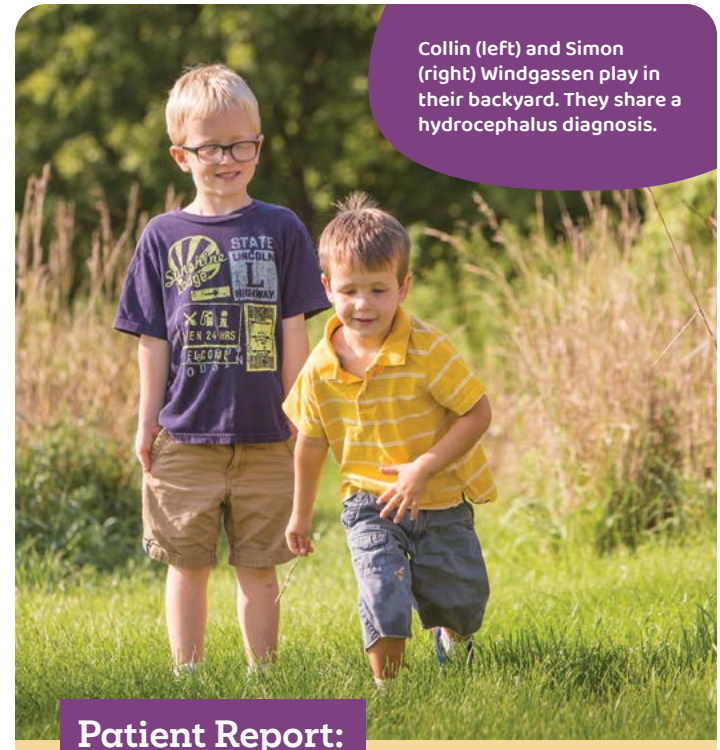
The Gillette neurosurgery team sees conditions including:

- Arachnoid cysts
- Arteriovenous malformations and other cerebral vascular conditions
- Birth brachial plexus injury
- Brain injuries and related neurotrauma
- Cerebral palsy
- Chiari malformation
- Complex movement disorders like dystonia
- Craniosynostosis
- Dandy-Walker syndrome
- Epilepsy and seizures
- Hydrocephalus
- Macrocephaly
- Moyamoya syndrome
- Spasticity
- Spina bifida
- Spinal cord abnormalities like tethered spinal cord
- Spinal cord injuries and related neurotrauma

Prenatal Neurosurgery Consultations

Because some of the conditions treated by neurosurgery are diagnosed during pregnancy, Gillette neurosurgeons also offer prenatal consultations and diagnosis. During these consultations, families meet with a neurosurgery provider to discuss the medical condition and, if appropriate, treatment options and a care plan.

Online Referral Form
gillettechildrens.org/referral



Collin (left) and Simon (right) Windgassen play in their backyard. They share a hydrocephalus diagnosis.

Patient Report:

A Shared Congenital Hydrocephalus Diagnosis

Collin and Simon Windgassen, born three years apart, were both diagnosed with hydrocephalus at age 1. Collin was diagnosed when his pediatrician became concerned about his unusually large head size. Testing at Gillette Children's confirmed hydrocephalus, and pediatric neurosurgeon Patrick Graupman, MD, was tapped to lead his treatment plan.

As for Simon, his mom Laura says at about 6 months old, he began crying more than usual. Soon after, he began throwing up as often as five times a day. Worried, Simon's parents quickly made an appointment with Gillette. When Simon received his diagnosis of hydrocephalus just like Collin, "It was so easy to look to Dr. Graupman and say, 'Go do your thing,'" shares his mom.

Same Condition, Different Courses of Treatment

In addition to their shunt placements, Collin and Simon both underwent surgery to address their Chiari malformations at age 3. Despite Collin and Simon sharing a condition, Simon has had a few more bumps in the road than his older brother. "Simon has needed six revision surgeries due to complications with his shunt," Laura recalls.

More than anything, Laura expresses gratitude to Simon's neurosurgery team for trusting her instincts. "I can call and say, 'I know something's wrong with my child,' and they'll get us in that day."

Expanding Cerebral Palsy Care

Specialists at Gillette's Cerebral Palsy Institute are focused on advancing research and innovation

Gillette Children's Cerebral Palsy Institute is committed to pursuing the brightest possible future for individuals who have cerebral palsy (CP). As part of this important work, Gillette has tapped neurosurgeon **Patrick Graupman, MD**; Medical Director of Research **Jennifer Laine, MD**; and Director of Research **Joyce Trost, PhD**, to provide vision and direction for producing and assessing rigorous research within the Cerebral Palsy Institute.

A Model to Mirror

Because Gillette already has seven different research programs, the biggest challenge was gathering each program together for more efficient collaboration. "One of the key challenges of the Cerebral Palsy Institute is that Gillette is so diverse and so broad," Dr. Trost says. "But working together and engaging with the diverse expertise is the real difference-maker."

Dr. Graupman adds, "Our patients are often complex and require collaborative, multi-disciplinary care, and our research needs to similarly benefit these patients. That is really what sets our CP research apart—our research model parallels our clinical care model: collaborative and multidisciplinary."

Patient-Powered Research

A new Cerebral Palsy Institute initiative seeks to engage patients and their families in all parts of the research process. This style of research design is more advanced outside of the United States, but very few, if any, are engaging populations with developmental disabilities.

The collaborative relationship between Gillette researchers and providers means children who have complex conditions get an expert, evidence-based care plan.

"We're looking to involve patients as truly active partners in the research process," says Jennifer Laine, MD.

Patrick Graupman, MD

Jennifer Laine, MD

Joyce Trost, PhD

"We're inviting patients and their families to not just participate in research, but to partner with us in asking the right questions, figuring out the protocol, evaluating the data, and presenting the research," Dr. Laine says. "We're looking to involve patients as truly active partners in the research process."

Different Initiatives, Same Goal

When asked what ideas they have been most excited by during discussions of the future of Cerebral Palsy Institute research, each leader had a different response, but each of them tied it back to the benefit for patients.

"For CP specifically, there is a lot of innovative technology that shows promise," Dr. Graupman says. "For example, a brain-computer-spinal interface could be a future treatment modality for CP. With this, patients could have greater control over their muscles and movement."

Dr. Laine says, "for me, I want to have research holistically integrated into our clinical care, so every patient who comes to Gillette would have the opportunity to participate in some sort of research to help inform care for future generations."

"The overall goal of the Cerebral Palsy Institute is to, in 10 years, see significant advancement in research, knowledge translation, and care delivery," says Dr. Trost. "And, after integrating corresponding data, including standardized outcome measures into our care model, we can then leverage health informatics to the greatest extent, creating a learning health system designed specifically for individuals who have CP."

World-Class Rare Disease Care at Gillette

Breakthroughs in treatments, medications, and therapies

Bennett Dahms and her parents appreciate the expert Rett syndrome treatment they found at Gillette.

Gillette Children's is leading the way in new treatments, medications, and therapies to help improve the lives of children diagnosed with rare diseases. This leadership makes Gillette a strong partner for primary care providers and pediatricians seeking expert treatment plans for their patients who have complex and rare medical conditions.

"Rare diseases are actually common at Gillette, and we're exploring exciting new treatments and therapies to really revolutionize rare disease care," says Gillette complex care pediatrician, **Arthur Beisang, MD**.

In the United States, a rare disease is defined as a condition that affects fewer than 20,000 people. One in 20 people will live with a rare disease at some point in their life.

Gillette is known worldwide for its expertise in care for children diagnosed with rare diseases, such as spinal muscular atrophy (SMA), acute flaccid myelitis (AFM), Legg-Calve Perthes disease, Prader-Willi syndrome, and other conditions. Gillette is one of just 18 clinics in the U.S. designated as a Clinical Research Center of Excellence by the International Rett Syndrome Foundation (IRSF).

New Treatments and Therapies at Gillette

"It's a very interesting time because the future of rare disease care is about biological manipulation with DNA and RNA modifications," Dr. Beisang says.

Recent breakthroughs in genome editing, such as CRISPR and other techniques, allow genetic material to be added, removed, or altered at particular locations in the human genome. Genome editing is in its infancy and is still being debated and developed.

"One of the exciting things we're starting to do at Gillette is look at how we can rapidly improve skills for many rare disease patients once they get therapy," Dr. Beisang says.

"This is a brand-new area, and it's very exciting because a lot of people around the country are not doing this," he adds. "With our excellent therapies program, we're really in a position to enhance learning in this area and become a leader in what I call 'habilitative care,' as opposed to rehabilitative care."

Gillette is one of just 18 clinics in the U.S. designated as a Clinical Research Center of Excellence by the International Rett Syndrome Foundation (IRSF)

Gillette provides rehabilitative care to help children regain skills and strength. Habilitative care and therapy would help children attain new skills they never possessed such as walking, talking, and muscle control.

A Possible First Medication for Rett Treatment

Dr. Beisang and his colleague, Gillette pediatric neurologist **Tim Feyma, MD**,

co-direct the Gillette Children's Rett Center of Excellence. Dr. Feyma is the principal investigator on trials of a new medication called Trofinetide. Dr. Beisang says, if approved by the Food and Drug Administration (FDA), it would be the first therapeutic medication for Rett syndrome.

"Trofinetide helps increase the connections between the neurons and makes the nerves more robust," Dr. Beisang explains. "That will translate into improving the coordination and speaking skills of Rett patients. We're very excited."

The FDA is scheduled to review the Trofinetide trial in March 2023. Gillette has been involved in the research into Trofinetide from the initial study through the various phases of the drug trial.

Rett syndrome is a rare condition that affects the brain's growth and development. Symptoms typically develop between 6 and 18 months of age, and about 95% of children diagnosed with Rett are girls.

A Leader in Rare Disease Research and Innovations

Currently there are no approved treatments for Rett syndrome, but Gillette, along with Boston Children's Hospital and Baylor College of Medicine, is the site of a National Institutes of Health (NIH) natural history study examining Rett patients. This NIH study is continuing to gather biological samples for possible detection of a biomarker for Rett patients.

According to Dr. Beisang, much of this renewed energy around finding new treatments, therapies, and cures for rare diseases comes from what he calls "the wonderful patient groups and families." Gillette has a history of listening to and collaborating with patients, families, and referring providers to focus research and innovation.

Helping Families Process Their 'New Normal'

The extensive Gillette neurology team, including pediatric neurologists **Randal Richardson, MD**, and **Jamie Eskuri, MD**, keep Gillette on the leading edge of medical breakthroughs in helping patients with new rare disease treatments.

Dr. Richardson is involved in clinical trials for groundbreaking treatments for the muscular disease spinal muscular atrophy (SMA). Gillette was among the limited number of providers involved in the expanded access program to treat patients with SMA Type 1 before the FDA officially approved the drug Spinraza™ in December 2016. Once Spinraza was approved as a treatment, Dr. Richardson became a trailblazer to assure that all children in Minnesota are screened for SMA at birth, unless their parents opt out of the newborn screening.

"The future of rare disease care is about biological manipulation with DNA and RNA modifications," says Arthur Beisang, MD.

"The fulfilling part of the work we do in neurology," Dr. Eskuri says, "is the emotional and social help we can provide parents and children. One of our main roles is to help families process their 'new normal' and to provide the best diagnosis and care plan for a child who has a rare disease."

Making Life Easier

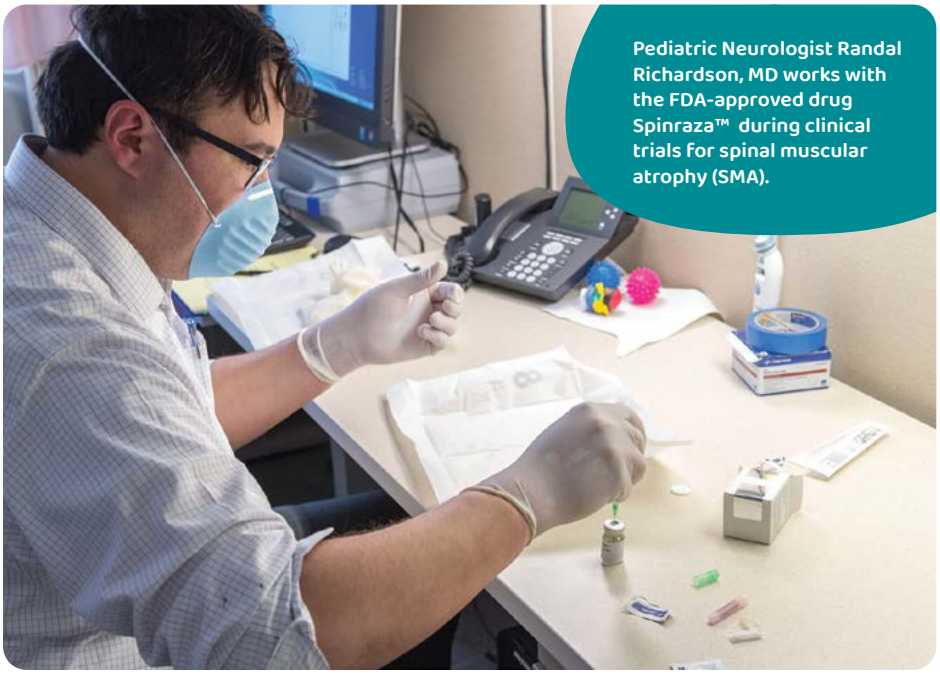
"Our patients at Gillette traditionally have had a lot of neurologic disorders," Dr. Beisang says. "Not just cerebral palsy, but global developmental delays of all kinds. With the advent of genetic testing, we're now identifying rare diseases in that population."

"The main work we're trying to do is to make life easier for patients and families of kids with rare diseases."

Referrals Forge Trusted Relationships

The team at Gillette wants primary care physicians to know referring a patient to Gillette is the start of forging deep and trusted relationships for providers and patient families.

"I practiced as a general care physician before coming to Gillette full time," Dr. Beisang says. "I understand the demands of seeing many patients in a short amount of time in a general clinic. A referral to the Gillette complex care clinic provides the opportunity for another set of eyes to help care for your most complicated patients. Together we can provide a higher quality of care."



Pediatric Neurologist Randal Richardson, MD works with the FDA-approved drug Spinraza™ during clinical trials for spinal muscular atrophy (SMA).

To learn more about rare disease care and research at Gillette, call **651-325-2200**.

New Opportunities for Muscle Quality Research

Gillette staff have received a new grant from the American Academy of Cerebral Palsy and Developmental Medicine

The American Academy of Cerebral Palsy and Developmental Medicine (AACPDM) awarded a grant to several Gillette Children's staff to begin investigating muscle quality and function in people who have cerebral palsy (CP) before spasticity treatment to the gastrocnemius. They will use a new technique called an ultrasound-guided microbiopsy in this research. This ongoing study is bolstered by a recently completed pilot study on the same topic.

The Gillette team, led by clinical scientist **Liz Boyer, PhD**, also includes Gillette physicians **Tom Novacheck, MD**, and **Marshall Taniguchi, MD**; two University of Minnesota researchers, Sarah Greising, PhD, and Christiana Raymond-Pope, PhD; as well as a physician mentor from Belgium, Anja van Campenhout, MD, who has previously performed gastrocnemius microbiopsies on children with CP.

The Importance of Maintaining Muscle Quality

Abnormal neuromuscular tone adversely affects function in individuals with CP, prompting many to undergo botulinum toxin injections or selective dorsal rhizotomy (SDR) ,but animal and human studies have shown that botulinum toxin may cause deleterious effects on muscle size and quality.

Muscle strength is one of the top predictors of gross motor ability and strength is a function of muscle quality, not just size. Therefore, muscle properties should be measured longitudinally in these patients. However, a study of this nature has yet to be done. The Gillette study will begin closing this gap by gathering baseline measures of muscle quality (ultrasonographical, histological, or biochemical) and gross motor function.

"There's not much literature on pediatric muscle properties, and so often when we are trying to establish if a muscle is healthy or within typical ranges, we can't really tell, " Dr. Boyer says. "This study is more rigorously designed, so we can get better answers from better science."

Researchers' Current Goals

The research funded by the AACPDM grant has two specific aims. First, Dr. van Campenhout provided training for physicians to become proficient in the ultrasound-guided muscle microbiopsy technique.

For the second aim, the team will obtain baseline muscle microbiopsies and functional measures in up to 10 individuals with CP and up to 5 neurotypical controls. By capturing participants' muscle properties before they undergo intervention, the team will have baseline data for larger longitudinal studies to compare post-intervention muscle quality.

"Because we are finally collecting that baseline, untreated muscle properties and function, we can, with time, determine if treatment is doing something positive, negative, or having no effect on the muscle," Dr. Boyer says.

The AACPDM-funded research is estimated to be completed in December 2023.

Explore more ongoing Gillette research projects at **gillettechildrens.org/research**.

Muscle Biopsy Pilot Study Inspires Future Work

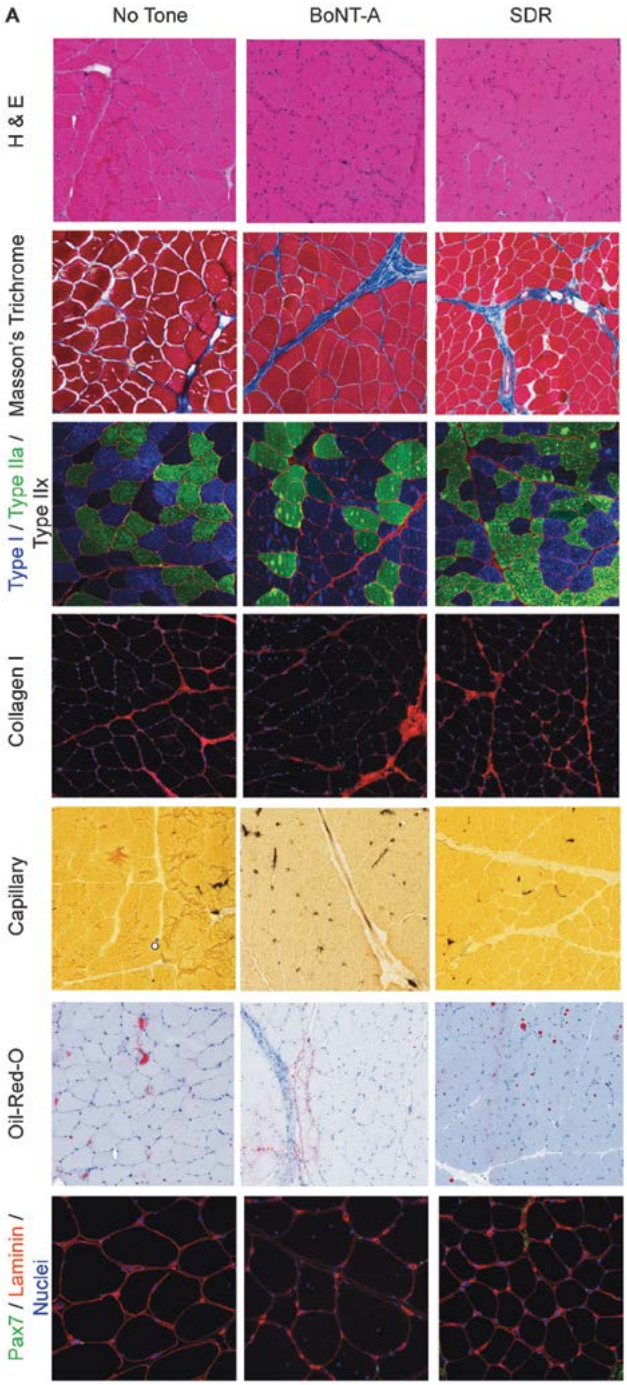
Using generous donations from the Gillette Children's Foundation, a pilot study paved the way for deeper investigation into muscle properties of individuals who have CP.

Muscle contractures, which can negatively impact gait and function, are a hallmark characteristic of individuals with CP. Treatments (e.g., botulinum toxin, selective dorsal rhizotomy (SDR), musculotendinous lengthening) are often sought to address or prevent these impairments, though studies and Gillette physician experience suggest these treatments do not guarantee prevention of future contractures.

Furthermore, animal and human data suggest that botulinum toxin may cause short- and long-term muscle atrophy, fatty infiltration, and increased fibrosis in these already smaller and functionally impaired muscles. Part of the reason that contractures are hard to prevent thus far may be that the pathogenesis of contractures in CP remains elusive.

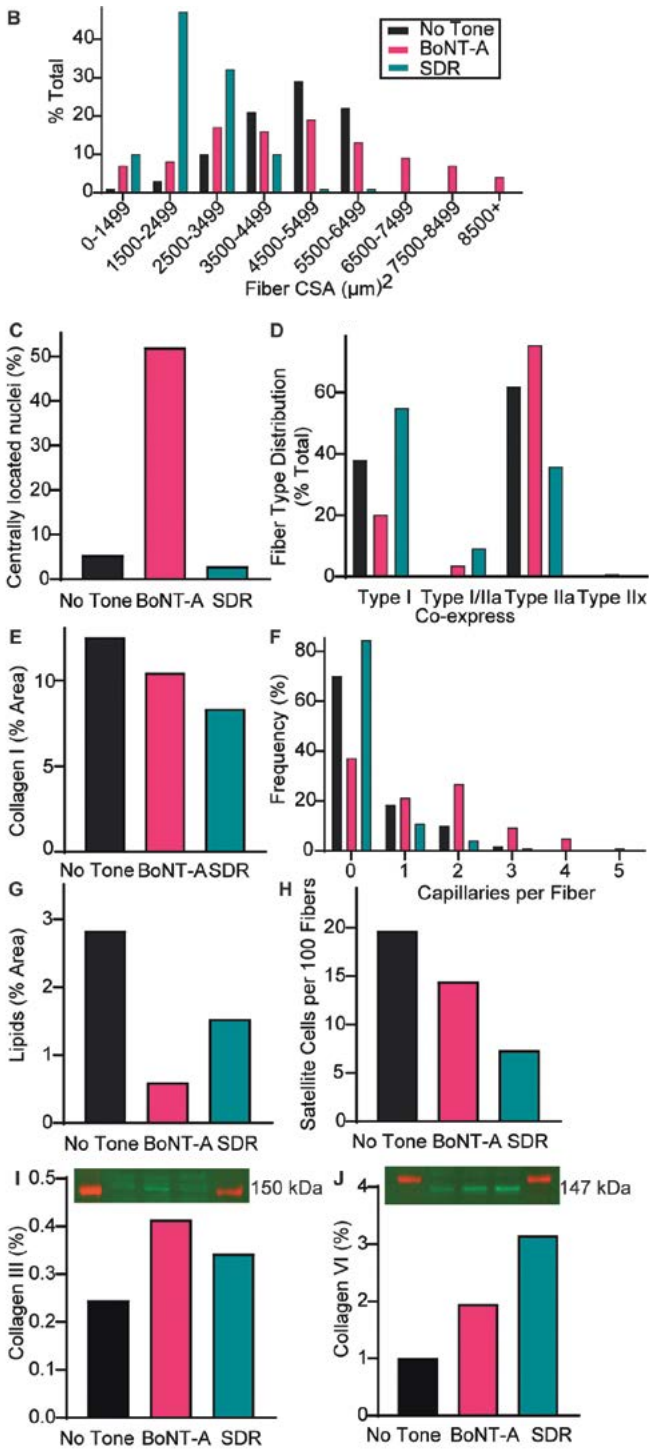
The study "Skeletal Muscle Properties After Various Tone Management Approaches in Individuals with Cerebral Palsy" looked at the muscle properties of the gastrocnemius in three children who had undergone different tone management approaches: 1) repeated botulinum toxin injections (BoNT-A), 2) SDR, or 3) no tone management (NO TONE).

The pilot study did not establish causation like the AACPDM-funded study (left) is meant to, but it did provide some clues about potential causal factors of the observed muscle properties. While all three participants had plantarflexor contractures and weakness prior to the biopsy, the largest differences observed between participants were for fiber cross-sectional area, fiber type, lipid content, satellite cell density, and centrally located nuclei. Capillary density, collagen area, and content, and muscle protein content were similar across participants. Several muscle properties appeared to deviate from normative data reported in the literature, though age- and muscle-specific references were sparse.



Images from top to bottom depict:

1) Hematoxylin and eosin to identify nuclei (dark blue/purple) compared to muscle (pink)
2) Masson's Trichrome stain to distinguish between muscle (red) and collagen (blue)
3) Myosin heavy chain stain to determine fiber types (blue: type I, green: type IIa, black: type IIx)
4) Collagen type I stain as one method of determining collagen presence (red)
5) Capillary staining to determine capillary density
6) Oil-red-o stain to determine presence of fat cells (pink/red)
7) Stain for satellite cells, i.e. muscle stem cells (green)



Representative histological images from each participant. Graphical depiction of quantitative analyses for the outcome variables.

Easing Growing Pains

How and when to transition medically complex patients from pediatric to adult care

Long-time Gillette patient Joe Carr uses a communication device to interact with his family, friends, and health care providers.

Tori Bahr, MD

The process of transitioning patients from pediatric to adult care requires a thoughtful plan—one that provides patients and their families with the skills and empowerment needed to navigate their well-being. This is especially true for patients who will not be able to live on their own; however, much of the literature surrounding this transition focuses on patients with a single common diagnosis or medically complex individuals who will live independently.

Tori Bahr, MD, medical director of pediatrics for Gillette's Complex Care and Transition Clinic, has studied how and when to best transition medically complex pediatric patients who will not be able to live independently. This population includes patients with complex diagnoses like severe cerebral palsy, muscular dystrophy, and chromosomal anomalies with global developmental delays and cognitive delays.

Building a transition team

Dr. Bahr says that transitioning care is much like a team sport, where the patient relies on multiple players to achieve a goal. An extensive transition team is required to meet the patient's needs, including resources from both within and outside of the clinic. This team centers around the patient and their parents/guardians and extends to include several people, such as complex care providers, primary care providers, specialists, social workers, rehab therapists, therapeutic recreation specialists, the school special education team, nurse care managers, and psychologists. The team works together to help the patient plan for establishing resources and living a life with as much independence as possible. It is suggested that providers begin having these conversations with families and patients in their early teen years, around ages 12–14.

An age-by-age guide

Below is a chart to help providers conceptualize which topics should be addressed with patients that will help them to make a smoother transition into adulthood as they age.

Age	Topics for discussion
12–14	• Identify patient's abilities • Work on developing age-appropriate health care skills such as knowing their condition and medications and why they have them
14–16	• Build on health care navigation skills • Gather information on age cutoffs for current care team
16–18	• Address guardianship • Provide education around the adult health system
18–21	• Identify an adult primary care provider • Transition specialists (ideally 1–2 every 6 months)
21+	• Complete the transition of specialists • Check in and track success

To learn more about how to help your pediatric patients transition into adult care, contact Gillette's Transition of Care team at **gillettechildrens.org/conditions-care/transition**

Searching for Answers

The Jama family found the expert rare disease care they needed at Gillette Children's

Amattulah Jama is able to join her siblings for fun at the park, thanks to a comprehensive Rett syndrome treatment plan.

Before her daughter Amatullah was born, Bisharo Jama prepared for her arrival in the same way she had for Amatullah's three older siblings. Amatullah would have an aqiqah ceremony performed in her honor— an Islamic tradition of celebrating a new life by feeding one's community, with a focus on those in need.

Amatullah's birth and first few months of life went by smoothly. At a few months old, Amatullah seemed just as chubby, beautiful, and healthy as her siblings were at her age. But then she started to change in ways Bisharo never anticipated.

A Growing Concern

Bisharo went from cheering Amatullah on as she learned to grab toys and books to watching helplessly as Amatullah forgot how to do those things—opting instead to keep her hands in her mouth. Amatullah soon started to miss more early-childhood milestones. At 6 months old, it became clear to Bisharo that Amatullah wasn't nearly as active as her siblings had been at her age.

Doctors told Bisharo it was too soon to worry because every child progresses at their own pace, so she continued with normal life while monitoring Amatullah closely. Then the crying began.

"It was nonstop," Bisharo says. "She was inconsolable." Soon after the crying, Amatullah began losing her ability to breastfeed. After a year of the regression and crying, Amatullah's primary doctors referred Bisharo to Gillette Children's for answers.

At Last, a Diagnosis

The regression of skills that Amatullah experienced is one of the telltale signs of Rett syndrome in its early stages. However, many of the early symptoms can be attributed to several other conditions, making it challenging to diagnose in infancy. As one of just 18 U.S. hospitals designated a Clinical Research Center of Excellence by the International Rett Syndrome Foundation, Gillette was the best place Amatullah could be.

Nicole Williams-Doonan, MD, a pediatric neurologist at Gillette, diagnosed Amatullah with Rett syndrome at age 2 in July 2013. This was an important first step in developing a comprehensive treatment plan for Amatullah.

A Mother's Promise

Bisharo finally had answers and now faced the reality of what Amatullah's future would look like. As soon as she started hearing things like 'Your daughter won't be able to walk or talk,' Bisharo made a promise to herself and Amatullah.

"I was going to do everything in my power to provide the best care and opportunities for my daughter," Bisharo says. "And that started with Gillette on my side." Amatullah worked hard each time she came to Gillette for an appointment. Her physical therapist worked with her in the therapy pool and on land. In occupational therapy, she worked on her grip, and speech therapy helped her communicate.

Despite being told her daughter would likely never walk, Amatullah can take independent steps. "Every day I see her get stronger," says Bisharo. "Now when we take her to the park to walk, her siblings and I cheer her on and watch her face light up with each step she takes."

Although there is not yet a cure for Rett syndrome, treatment can help slow the loss of abilities, improve or preserve movement, and encourage communication skills. Specialists at Gillette work closely with groups such as the International Rett Syndrome Foundation and the Midwest Rett Syndrome Foundation, to ensure that patients are receiving the best course of treatment.

For more information and resources about Rett syndrome:

Read more about our ongoing Rett efforts on page 6.

WINTER 2023

Gillette
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**

To refer a patient

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

Refer online at
gillettechildrens.org/referral

GILL-002

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Internal: 010605
200 University Ave E
St. Paul, MN 55101

Gillette
Partners in Care
WEBINAR

Participate in Gillette Partners in Care Webinar

Developmental Orthopedics: In-Toeing, Out-Toeing, and Lower Extremity Alignment with **Laura Tillman, DNP, APRN, CPNP**

Course Objectives

At the completion of this webinar, participants should be able to:

- Describe the etiology, natural history, and treatment of in-toeing and out-toeing.
- Describe lower extremity examination techniques.
- Discuss typical coronal alignment (genu varum/valgum) and variations.
- Discuss when referral to orthopedics is warranted.