

gillette

Partners in Care

JOURNAL

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A Ketogenic Diet Success

Seizure management
for a genetic-based disorder

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On the cover: Lilah Schwab has a different view on life now that a novel treatment has brought her seizures under control.

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About Our Journal

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New Surgical Services Leadership at Gillette



Jo Barta, MD, has been named Gillette's new surgeon-in-chief and medical director of surgical services, and **Nick Nahm, MD**, has been named associate medical director (AMD) of surgical services. After many years of excellence in the position, **Kevin Walker, MD**, transitioned out of his role as medical director of surgical services while mentoring Drs. Barta and Nahm.



Dr. Barta's leadership is exceptionally aligned with becoming Gillette's first surgeon-in-chief. She received her medical education at the University of Minnesota in general surgery and plastic and reconstructive surgery followed by a fellowship in craniofacial and plastic surgery at Seattle Children's. She has been a leader in craniofacial plastic surgery both at Regions Hospital and the University of Minnesota and has been caring for patients at Gillette since 2019.



Dr. Nahm is also highly qualified to improve the quality and safety of care for our surgical patients. He received his medical degree at Case Western Reserve University and completed his residency in orthopedic surgery at Henry Ford Hospital. He completed three fellowships, including a Pediatric Orthopedic and Neuromuscular Fellowship at Nemours, as well as Limb Lengthening and Reconstruction at Sinai Hospital of Baltimore. He joined Gillette in 2022.

Gillette Welcomes New Executive VP of Operations and Chief Operating Officer

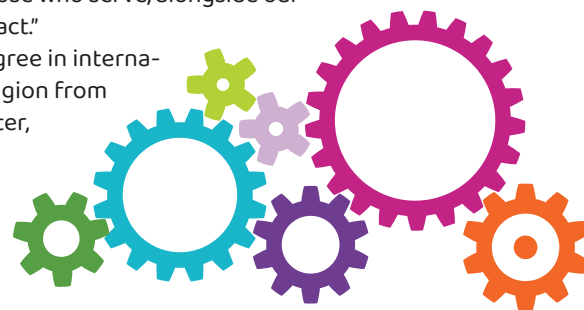


Gillette Children's welcomes **Kelly Morse Nowicki** as executive vice president of operations and chief operating officer.

Before joining Gillette Children's, Nowicki spent more than 20 years at Mayo Clinic in Rochester. Most recently, she was responsible for shared services and hospital operations across Mayo campuses in Minnesota, Arizona, Florida, and Wisconsin. Before joining Mayo, Nowicki was CEO of the Girl Scout Council in Rochester.

"Kelly's experience building high-performing operations and advancing patient-centered strategies will be invaluable as we deliver on Gillette Children's mission," says Barbara Joers, president and CEO. "Her leadership will help us strengthen both the daily experience of those we serve and those who serve, alongside our long-term vision for growth and impact."

Nowicki earned her bachelor's degree in international business and comparative religion from Gustavus Adolphus College in St. Peter, Minnesota, and a master's degree in business and clinical ethics from the University of Chicago.



Announcing New Chief Medical Director of Adult Services



Giancarlo Perez-Albela, MD, started as Gillette's new chief medical director of adult services in January 2026, succeeding **Jill Gettings, MD**.

Dr. Perez-Albela is a graduate of the Universidad de San Martín de Porres in Lima, Peru. He completed his residency in physical medicine and rehabilitation (PMR) at New York Medical College and a Fellowship in spinal cord injury at Jackson Memorial Hospital at the University of Miami. He joined Gillette in 2019 and has been active in many operational, quality, and safety task forces

and committees, as well as leading the adult Spina Bifida Clinic.

Dr. Gettings has served as the chief medical director of adult services since 2018. She will stay on as a part-time adult PMR clinician to support Dr. Perez-Albela and the adult team.



Gillette Children's Earns Reverification as a Level I Specialty Musculoskeletal Children's Surgical Center

Gillette Children's is proud to have been reverified by the American College of Surgeons (ACS) as a **Level 1 Specialty Musculoskeletal Children's Surgical Center** — the highest designation of its kind. This achievement reflects our ongoing commitment to delivering exceptional, safe, and specialized surgical care for children with musculoskeletal conditions.

The ACS Children's Surgery Verification (CSV) Program recognizes hospitals that meet rigorous standards in pediatric surgical care. To earn this distinction, centers must demonstrate strong multidisciplinary collaboration, robust safety practices, comprehensive data monitoring, and a care environment equipped with the full range of pediatric resources required for children with complex needs.

At Gillette, quality and safety are deeply embedded in our approach to care. Our surgical teams include highly trained specialists dedicated to continuous improvement. Through regular Surgery Performance Improvement and Patient Safety (SPIPS) committee reviews, our surgeons evaluate outcomes, monitor best practices, and identify new opportunities to enhance the surgical experience for patients and families.

This reverification affirms our longstanding commitment to advancing pediatric surgical care — and to ensuring that every child we serve receives the highest standard of treatment.

CARF Awards Gillette Children's Three-Year Reaccreditation for Rehabilitation Excellence

Gillette Children's has again been awarded a three-year Commission on Accreditation of Rehabilitation Facilities (CARF) reaccreditation following the 2025 survey. This accreditation, which extends through November 2028, places Gillette among a select group of inpatient rehabilitation programs in the nation recognized for excellence in both **pediatric specialty** and **brain injury specialty** care.

This achievement reflects our unwavering dedication to improving the lives of the children and families we serve. Gillette's integrated inpatient rehabilitation program — supported by the nation's highest concentration of pediatric rehabilitation medicine specialists — continues to provide a comprehensive continuum of care designed to support each child's physical, emotional, and developmental needs.

CARF surveyors praised the strength of our culture and our organization-wide commitment to patient- and family-centered care, noting:

"Throughout Gillette Children's, it is evident, from top to bottom, that the care is focused and attentive to the patient and family. This drives everything that is a part of the organization, how decisions are made, and the vision for the future. This is noteworthy."

Families also shared powerful reflections about their experiences, including:

"The team brought out the best in my child."

"They provided a custom program for my child's mental and physical health."

"The psychologist felt like a warm hug in her approach and support."

These voices highlight what matters most to Gillette: the meaningful difference our teams make every day.

CARF surveyors additionally recognized Gillette's leadership in advancing pediatric rehabilitation medicine on both national and global levels — citing our research, innovation, and evidence-based practices as models for the field.

We are honored by this reaccreditation and remain committed to pushing the boundaries of what's possible in pediatric rehabilitation — so every child can grow, heal, and thrive.

Two New Titles Released in Gillette Children's Healthcare Series

In 2025, two new books were added to the Gillette Children's Healthcare Series, copublished with Mac Keith Press, bringing the total to seven of the planned nine-volume collection. The final two titles are expected in 2026.

Epilepsy: Understanding and Managing the Condition Across the Lifespan

Published in March 2025, this guide by Charbel El Kousseifi, MD, Cheryl Tveit, and Anna Halderson blends medical expertise

with personal experience, following the story of Emma, a young adult with epilepsy. Reviewer Maria Roberta Cilio, MD, PhD, praised the book for offering "comfort, guidance, and knowledgeable support — the art of care."

Scoliosis: Congenital, Neuromuscular, Syndromic, and Other Nonidiopathic Types

Released in October 2025, this volume by Tenner Guillaume, MD, Walter Truong, MD, Danielle Harding, PAC, Lily Collison,

and Cheryl Tveit provides best-practice insights and shares experiences from more than a dozen families. Brian Snyder, MD, PhD, called it "a vital educational resource...emphasizing evidence-based best practice."

Visit gillettechildrenshealthcare-press.org to learn more and browse the rest of the catalog.

Federal Newborn Screening Panel Adds DMD and MLD

The U.S. government has added **Duchenne muscular dystrophy (DMD)** and **metachromatic leukodystrophy (MLD)** to the national **Recommended Uniform Screening Panel (RUSP)** — a milestone that will expand early detection for two progressive, often fatal childhood conditions.

For Gillette Children's, this marks a pivotal advancement for the children and families we care for.

"Early detection changes everything," said Jamie Eskuri, MD, pediatric neurologist at Gillette Children's who treats children with DMD. "By adding DMD and MLD to the RUSP, families nationwide will finally have access to the same lifesaving opportunities that only a handful of states have offered until now."

DMD is the most common form of muscular dystrophy in children, while MLD is a rare, progressive genetic disorder of the nervous system. Both conditions benefit greatly from early diagnosis — leading to earlier treatment, participation in clinical trials, and improved long-term outcomes.

Currently, only Minnesota, Ohio, and New York screen newborns for DMD. Federal adoption of the recommendation is expected to greatly expand access to the screening across the country, enabling earlier identification and quicker referrals to specialty centers like Gillette.

As an **MDA Care Center** and a nationally recognized leader in treating complex pediatric neurological conditions, Gillette Children's is uniquely positioned to support families following a diagnosis — helping them navigate care, treatment options, and emerging research.

Gillette Children's Expands Leadership in Rare Neurological Care with GLUT1 Designation

Gillette Children's has been officially designated as a Collaborative Care Center by the **GLUT1 Deficiency Foundation**, joining a growing network of clinical partners dedicated to improving care for individuals living with GLUT1 deficiency. The designation recognizes Gillette Children's for its comprehensive, multidisciplinary approach and its commitment to centering patients and families in all aspects of care.

GLUT1 deficiency is a rare genetic disorder that impairs the brain's ability to transport and use glucose as fuel. It can cause severe neurological issues, such as seizures, movement problems, developmental delays, and cognitive impairment. GLUT1 deficiency often begins in infancy. The main treatment is a **ketogenic diet** (high fat, low carbohydrate) to provide alternative fuel for the brain, which typically yields significant improvements among patients.

"We are honored to join the GLUT1 Deficiency Foundation's Collaborative Care Network," said **Nicole Williams Doonan, MD**, a pediatric neurologist at Gillette Children's. "This designation reflects our team's dedication to providing high-quality, family-centered care for children with rare neurological conditions. We look forward to contributing to shared research efforts and learning alongside other centers to advance the understanding and treatment of GLUT1 deficiency."

As part of the designation, Gillette Children's will participate in several ongoing network initiatives, including clinical work groups focused on developing a disease severity scale, establishing a core outcome set to support clinical trial readiness, and enhancing data collection to strengthen the foundation's natural history research efforts.

This designation underscores Gillette Children's continued commitment to advancing care for children with rare and complex neurological disorders.



Early, Function-Focused PMR Referrals Help Kids Gain Strength, Skill

Tara Buettner says most people find it remarkable when her 13-year-old son, John, fondly recalls the six weeks he spent in the Gillette Children's Inpatient Rehabilitation Unit recovering from selective dorsal rhizotomy (SDR) surgery.

Gillette Children's and its Cerebral Palsy Institute is one of the top providers of selective dorsal rhizotomy — a procedure that treats muscle spasticity caused by abnormal communication among the brain, spinal cord, nerves, and muscles. Gillette is the only comprehensive, pediatric-focused inpatient rehabilitation facility in the Twin Cities and is one of only two pediatric facilities in Minnesota accredited by the Commission on Accreditation of Rehabilitation Facilities (CARF).

John was 18 months old when he was diagnosed with spastic diplegia cerebral palsy and referred to Gillette Children's. For him, the lower part of his body, including his legs, hips, and feet, is the most affected. "From 18 months of age until he was 5, John was getting Botox [botulinum toxin] injections at Gillette to help with the spasticity in his legs," Tara says. The Botox injections brought some relief, but Gillette neurosurgeon Peter



"John just LOVED his inpatient rehab stay," Tara recalls. "He loved the people, the room, and everything about the experience."

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John uses a "zero-gravity" harness, which supports his weight while he works on his gait during a physical therapy session.



Where Does PMR Fit in Pediatric Care?

Physical medicine and rehabilitation (PMR) is a medical specialty that helps to restore movement and ability following an injury, illness, or major surgery. At Gillette Children's, our pediatric rehabilitation experts care for children and teens who experience congenital or acute-onset loss of functioning. Children and teens who find PMR beneficial include those who have:

- Amputations or limb loss
- Birth brachial plexus injury
- Brain injury, spinal cord injury, and related neurotrauma
- Cerebral palsy
- Chronic pain
- Spina bifida
- Complex movement disorders that need interventions, such as deep brain stimulation (DBS) or intrathecal baclofen pump placement
- Major surgery, such as SDR or single-event multilevel surgery (SEMLS), used to treat orthopedic and neuromuscular conditions
- Illnesses like acute flaccid myelitis or transverse myelitis

Learn more or refer to the Gillette PMR team: 651-400-2525.

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Kim, MD, suggested more progress could be made in alleviating the spasticity with SDR surgery.

John's surgery was successful, and, like all Gillette patients who have the procedure, he spent six weeks postsurgery in a rigorous, comprehensive inpatient rehabilitation program to build his strength and function and learn new skills. Studies

have shown that children experience better outcomes when treated in a pediatric-focused rehabilitation facility rather than a facility that treats both adults and children. But comprehensive inpatient rehabilitation for toddlers, children, and teens is a rare find in the Midwest.

Gillette pediatric rehabilitation experts offer comprehensive, pediatric-focused care in a clinical environment devoted to the highest standards of patient care and safety, with a focus on outcomes and impact. Our providers take care to design a patient- and family-centered care plan in collaboration with the patient's entire medical team, both within and outside Gillette. John and his

family were particularly impressed with how smoothly everything they needed came together.

"John just loved the rehabilitation therapy," Tara says. "In the evening, we would get a rundown of all the therapies and appointments John had the next day. It was amazing." She found the inpatient rehabilitation unit to be "well run and very organized. We enjoyed the evening activities and the visits from therapy dogs. I also appreciated having access to the prone carts that allowed me to take John outside for a bit of fresh air and to see the Gillette playground."

Today, John is in the eighth grade and advocates to ensure children who have disabilities have access to playgrounds. He works with Landscape Structures to test and design accessible playground equipment. "John is an old soul," his mother proudly proclaims. "His goal is to continue this work in the disability access area and be an engineer or designer one day."



Neurosurgeon Peter Kim, MD (left), maintains a strong clinical relationship with John.

Inpatient vs. Outpatient PMR: How to Choose the Best Option for Your Patient

For children like John, **PMR is the physician specialty that integrates function-first diagnosis, nonoperative management, care coordination, and longitudinal planning**, and it fits alongside your care plan for your patient, not after it.

While inpatient and outpatient PMR share many similarities, the main difference between the two is the **intensity** of the rehabilitative process.

- **Inpatient PMR** at Gillette Children's is recommended (and sometimes required) for pediatric patients who will benefit from the intensive, coordinated rehabilitation services of an expert rehab team in a hospital setting when recovery at home is determined to be inadequate for safe and proper recovery. An inpatient rehabilitation stay typically lasts several weeks and focuses on intensive, targeted treatments meant to restore key areas of functioning during hospitalization.
- **Outpatient PMR** consists of regular appointments for physical, occupational, or speech therapy while living at home and going about regular life. Outpatient PMR is ideal for children and teens whose functioning has not been significantly reduced by an illness or injury, who can gradually recover a loss of functioning, or benefit from ongoing

or short-term rehabilitation therapy to manage their injury or condition.

When our PMR experts identify a candidate for inpatient rehabilitation at Gillette, they look for patients who are 21 years old or younger who have:

- A need for the intense comprehensive and coordinated services of a medical rehabilitation team
- Reasonable expectations for functional improvement or benefit from available services
- An ability to physically and psychologically tolerate an intensive rehabilitation program, which includes **up to 900 minutes/15 hours of rehabilitation services every seven days** (at the discretion of the admitting provider)

No matter your patient's need, early referral supports earlier diagnosis, clearer goals, and faster access to the right mix of therapies, technology, and family supports — often all under one roof. As John's mom, Tara, put it, "We're grateful his care at Gillette allows him to build strength and plan for his future."

Learn more or refer to the Gillette PMR team: **651-400-2525**.

Implementing the Ketogenic Diet in Complex Pediatric Care

How Gillette Children's evaluates, initiates, and monitors ketogenic therapy for safe and effective management of epilepsy and metabolic disorders

For children with epilepsy and those with metabolic disorders, a medically supervised ketogenic diet may be indicated for symptom management, including as a means of reducing seizure activity.

Distinct from the fad keto diet for weight management (which emphasizes high protein, high fat, and low carbohydrates), the use of a ketogenic diet to manage a health condition is highly specialized and should be medically monitored.

The ketogenic diet mimics the effects of fasting by breaking down dietary fat to produce ketone bodies (ketones), putting the body into ketosis. High in fat, adequate in protein, and very low in carbohydrates, the ketogenic diet alters the body's metabolism to use fat/ketones as its primary source of fuel.

While known for its effectiveness as a treatment for epilepsy and seizure management, the ketogenic diet has proven beneficial for patients with a variety of metabolic disorders, including GLUT1 deficiency, Pompe disease, and pyruvate dehydrogenase deficiency.

Mechanisms of the ketogenic diet

The ketogenic diet is known to reduce seizure activity and may also have a role in disease modification. Its combination of mechanisms include:

- Increase in GABA
- Increase in adenosine levels
 - Decrease in DNA methylation
 - Improvements in cognition and sleep
- Inhibitory effects of fatty acids
- Activation of KATP channels
- Improvement in mitochondrial function
- Enhancement of TCA cycle function
- Reduction in oxidative stress

The Ketogenic Diet Clinic at Gillette Children's

Gillette Children's Ketogenic Diet Clinic assesses, plans, and implements the ketogenic diet for children who would benefit from its use. Through an interdisciplinary evaluation, the team



What is a Ketogenic Diet Ratio?

The ketogenic diet is often referred to in ratios of macronutrients. The ratio expresses grams of fat relative to the combined grams of protein and carbohydrates.

For example:

3:1 ratio =

three times the grams of fat to the combined grams of protein and carbohydrates

120 grams of fat:
18g protein
+ 22g carbohydrates

120:40 (i.e., 3:1)

Clinical significance:

Higher ratios mean more fat and fewer carbohydrates, which increase the risk of adverse side effects and reduces palatability. Lower ratios mean less fat and more carbohydrates, with lower risk of adverse side effects and generally better palatability. The goal of Gillette's ketogenic diet team is to find the lowest ratio that produces the best results for the patient.





During a follow-up, Dr. Williams Doonan assesses Lilah's response to the new diet regime.

Some of the biggest points covered are the patient's likelihood to benefit from the ketogenic diet, as well as the likelihood that the patient and their family will be able to successfully adhere to such a strict eating regimen.

determines candidacy by aligning the patient's clinical profile with family readiness and support.

The team reviews seizure frequency and patterns, prior medication trials, and relevant metabolic diagnoses, alongside nutritional status and growth considerations. Just as important, clinicians assess family readiness for a structured regimen, the ability to adhere to precise meal planning, and the availability of caregiver support.

Specialists in neurology, dietetics, pharmacology, and complex pediatrics, together with a nurse care coordinator, collaborate to create an individualized plan that balances clinical goals with feasibility. When a patient is an appropriate candidate, the team outlines the rationale for initiating the diet, expected timelines, and the shared responsibilities across the care team and family. This structured approach helps ensure that ketogenic therapy is introduced safely, tailored to the child's needs, and positioned for long-term success.

An example of the structured safety support inherent to the Ketogenic Diet Clinic includes inpatient initiation of the diet. Due to the stringency of the ketogenic diet and the need to customize it for the nutritional needs of every patient, patients

of the Gillette Ketogenic Diet Clinic are often hospitalized for a short time to begin the diet in a controlled, medically supervised setting. During their stay, patients and their families are educated on the use, mechanisms, and functions of the ketogenic diet for their conditions, and receive resources like recipes, guidance about medication while on the ketogenic diet, and support for what can be a challenging transition.

Which Patients Might Benefit from a Ketogenic Diet?

The ketogenic diet may be appropriate for:

- **Children with medically refractory epilepsy** who have not achieved seizure control with medications
- **Patients with specific metabolic disorders**, including GLUT1 deficiency, Pompe disease, and pyruvate dehydrogenase deficiency
- **Infants and young children** with early-onset seizures where metabolic therapy may be beneficial
- **Patients with limited pharmacologic options** or contraindications to additional anti-seizure medications

Early referral is encouraged when response to medications is limited and the family is open to dietary therapy.

To refer to Nicole Williams Doonan, MD, or request information about the Ketogenic Diet Clinic at Gillette, call **651-400-2525** or visit gillette.mn/referral.

When Every Month Matters: Fast-Track Developmental Evaluation for Infants and Toddlers

When an infant or young child shows differences in movement, muscle tone, symmetry, or milestone progression, families look to you to identify developmental delays as early as possible, even amid shortened visits and increasingly complex neonatal histories.

As pediatric primary care providers face these growing pressures, Gillette Children's **Developmental Evaluation Clinic** was designed to support that moment: a single, coordinated, multidisciplinary evaluation that helps clarify what's happening for your patient and how you and the patient's family can help.

Gillette Children's Developmental Evaluation Clinic clinician and pediatric neurologist Nicole Williams Doonan, MD, is keen to offer her expertise, when it means earlier treatment for infants and toddlers who have developmental delay or regression.

"At Gillette, we focus on getting infants and toddlers into treatment as early as possible to take advantage of the neuroplasticity of the developing brain. The earlier a child is diagnosed and begins treatment, the better their future function and quality of life," says Dr. Williams Doonan.

One visit, multiple perspectives

Unlike traditional referral pathways that may involve several sequential appointments, Gillette's Developmental Evaluation Clinic brings together three specialists for one coordinated visit from pediatric neurology, pediatric rehabilitation medicine (PMR), and physical or occupational therapy. The full team evaluates the child simultaneously, integrating neurologic, functional, and motor findings in real time. The result, Gillette clinicians say, is a clearer picture of whether a child is developing as expected — and, when they are not, a more direct path forward.

The model reflects a shift toward fulfilling parental expectations in pediatric subspecialty care: fewer handoffs, faster

diagnostic clarity, and earlier intervention during a narrow window of neurodevelopmental plasticity.

"These days, we're seeing parents who are more informed than ever, with higher expectations than ever. They know that early identification of physical developmental delays, especially in the first three years of life, can change their child's trajectory," says Dr. Williams Doonan. "That's why we're so excited about our Developmental Evaluation Clinic. In its first full year of operation, the clinic delivered timely diagnoses that supported comprehensive care planning, appropriate subspecialty referrals, and early long-term planning, allowing interventions to begin while patients are still young and most likely to benefit."

What to watch for

Gross motor development progresses from head to foot — head, trunk, extremities — and from proximal to distal. Movements generally become more precise, with primitive reflexes being replaced by more complex movements. In atypical development, this is not always the case. Additionally, if a child regresses in development, they should be urgently referred to a neurologist or specialty clinic like the Gillette Children's Developmental Evaluation Clinic.

The clinic is designed for **children with suspected or evolving physical/motor developmental concerns**, including infants and toddlers with risk factors or signs of neuromotor difference.

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Request an evaluation for a patient who shows differences in symmetry, muscle tone, or dexterity.

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Gillette's Developmental Evaluation Clinic can help assess neuromotor differences or delays.

get them back on track, get a care plan in place, or reassure families there is no need to worry."

A faster route to clarity

For families, the clinic offers either reassurance or a personalized treatment plan without months of fragmented appointments. For primary care providers, it offers a streamlined option when developmental questions arise early and answers matter most.

Why refer to Gillette Children's?

When a child needs additional workup or treatment, families benefit from being evaluated in a system built for pediatric developmental conditions. Gillette Children's is recognized for its expertise in evaluating and treating pediatric developmental and motor conditions and helping families achieve peace of mind or navigate the next steps with a multidisciplinary approach.

Common risk factors

Consider referral for children with any of the following histories:

- **Prematurity** (born before **33 weeks**)
- **Extended oxygen support** in a neonatal intensive care unit or upon discharge
- **Abnormal head ultrasound**
- **Illness at or around the time of birth**
- **Lack of oxygen to the brain** during/after birth (e.g., **hypoxic ischemic encephalopathy**)

Clinical signs and symptoms prompting referral

The clinic commonly evaluates children with:

- **Motor delays** (sitting, crawling, walking)
- **Muscle tone concerns** (high or low tone at rest)
- **Loss of previously acquired motor skills**
- **Coordination issues/clumsiness** or difficulty using one/both sides of the body
- **Persistent fisted hands**
- **Persistent head lag** that does not

improve, or difficulty holding the head up

- **Hand preference before 12 months**
- **Asymmetry** in posture or movement
- Other physical developmental delays or concerns related to movement and physical function

A delayed physical developmental milestone

occurs when a child does not achieve an expected skill (e.g., rolling over, sitting, crawling, walking) within the typical age range. "While some children may 'catch up' and acquire the skill, **missed milestones can also be early red flags** for more significant neuromotor concerns," says Dr. Gormley. "Whatever the concern is, it's better to evaluate the child as early as possible so we can



To refer, call **651-400-2525** or submit to Gillette Children's online referral form at **gillette.mn/refer**

Note: The clinic does **not** evaluate autism, behavioral concerns, or speech-only delays.

From Daily Seizures to Stability: Lilah's Ketogenic Diet Success Story

Eight-year-old Lilah Schwab loves to wrestle — her parents, siblings, and even her teachers and aides at school have all experienced “The Silencer,” Lilah’s wrestling alter-ego.

Lilah has also been wrestling with medical challenges since birth. As a newborn, she was placed on a CPAP machine, and within a day of coming home, her mother noticed her skin turning blue. Lilah turned blue again at the hospital, prompting an emergency helicopter transfer to a larger facility. Despite extensive tests and imaging, doctors found no clear cause. An EEG showed random apnea episodes but no definitive diagnosis. Lilah eventually returned home with an apnea monitor; although the apnea eased, she continued to experience concerning neurological symptoms.

A visit to Gillette leads to solutions

Eventually, Lilah was diagnosed with FBRSL1 gene disorder, which is known to cause epilepsy. She and her family later came to Gillette Children’s with a goal in mind: solve the big mystery of how to help alleviate Lilah’s seizures, which occurred nearly 100 times a

day. Medications did not work to control her seizures and left Lilah feeling agitated and grumpy. She and her family needed another solution.

The Schwab family met with pediatric neurologist Nicole Williams Doonan, MD, who immediately impressed them. “She showed us how compassionate she was and how much she wanted to solve the mystery,” Ariana remembers. “We felt so comfortable with her.”

Dr. Williams Doonan was excited to partner with the Schwabs to explore a ketogenic diet as a treatment option. The classic ketogenic diet is a specialized high-fat, low-carbohydrate diet that causes the body to continually produce ketones. Ketone production causes a state called ketosis, which decreases seizures in some children.

Ketogenic diet provides relief for Lilah’s seizures

Lilah began the diet with a four-day stay at Gillette, where her blood sugar levels, vital signs, and ketone levels could be closely monitored. During Lilah’s time at Gillette, a team of experts — including a dietitian — worked to help the Schwabs with keto-friendly menu planning, resources, and tips. Ariana and Ryan found recipes that allowed Lilah to enjoy things like birthday cake and favorite family meals.

“Lilah had an excellent response to the ketogenic diet,” says Dr. Williams Doonan. “Several years later, her seizures remain well controlled on the diet alone. Because her seizures started when she was a baby, finding an effective treatment has had an even greater impact on Lilah’s brain development, behavior, and quality of life.”

Lilah and her dad frequently visit with the team that monitors her diet and neurological status.

Every three months, Lilah visits Gillette for screenings to ensure she is still responding to the ketogenic diet in healthy and beneficial ways. Today, Lilah enjoys music class, watches Bluey (her favorite show), and eats her keto-friendly lunch in the school cafeteria with friends.

“Lilah’s care at Gillette and the keto diet have really improved her quality of life,” says Ariana. “Without her seizures progressing and impacting other parts of her brain, Lilah can relax and fall asleep at night. As her parents, we can feel comfortable leaving her with her grandparents and bringing her to school without a catastrophe happening. It’s been a big, big help.”

To refer to Nicole Williams Doonan, MD, or request information about the Ketogenic Diet Clinic at Gillette, call **651-400-2525** or visit gillette.mn/referral.



Gillette is able to help Lilah and her family with an unusual genetic disorder.





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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

Unsubscribe From Gillette Partners in Care Journal at gillette.mn/remove.

To refer a patient



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



Refer online at
gillettechildrens.org/referral

GILL-167111

New! Gillette Children's Provider Access Line

Quick clinical insights for your practice

Provider Access Line: 651-400-2525

Hours: Monday – Friday, 8:00 a.m. – 4:30 p.m.

Get rapid, peer-to-peer guidance on:

- Urgent appointments or admissions
- Recommended services for your patient
- Concerns about developmental delay
- Diagnostic testing insights and interpretation
- Medication questions
- Interim management until the patient is seen

Gillette Children's Provider Access Line is staffed by nurses, with a provider returning calls within 30 minutes. This service is intended for healthcare providers only.



Refer a patient for early
diagnosis of brain, bone, and
movement conditions.

