

gillette

Partners in Care

JOURNAL

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Winter 2025

An Infusion of Hope for Duchenne Muscular Dystrophy

How gene therapy Elevidys transforms lives amid risks, challenges, and new frontiers

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On the cover: Caleb Thompson receives gene therapy treatment for Duchenne muscular dystrophy at Gillette Children's.

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Chief Medical Officer & Executive Vice President, Clinical Affairs
Deborah Quanbeck, MD
Associate Chief Medical Officer

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Anesthesiology: Michael Angel, MD
Greater Minnesota Clinics: Andrea Paulson, MD
Integrated Care Services: Tom Novacheck, MD
Neurology: Tim Feyma, MD
Neurosurgery, Craniofacial, Plastics, and ENT: Peter Kim, MD
Orthopedics: Michael Healy, MD
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Surgical Services: Kevin Walker, MD

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Spine Institute: Tenner Guillaume, MD

About Our Journal

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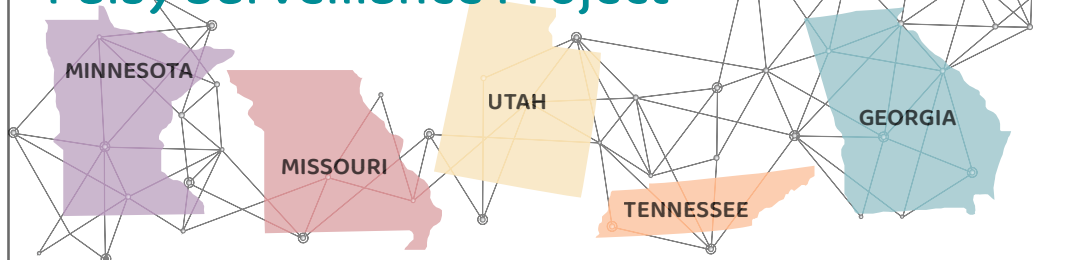


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CDC Visits Gillette for Cerebral Palsy Surveillance Project



Recently, the Centers for Disease Control and Prevention (CDC) visited Gillette Children's as part of a nationwide initiative to enhance public health surveillance of cerebral palsy through the Autism and Developmental Disabilities Monitoring (ADDM) Network. Gillette's partnership with the University of Minnesota's ADDM site reflects our deep commitment to advancing care for children with cerebral palsy. Gillette's collaboration with the University of Minnesota's ADDM site is helping drive this important initiative. Gillette research team members **Chantel Burkitt, PhD**, senior clinical scientist, and **Meghan Munger, PhD, MPH**, director of Outcomes, co-lead this project.

The CDC is coordinating cerebral palsy surveillance efforts across five ADDM sites: Utah, Minnesota, Missouri, Tennessee, and its CDC-managed site in Georgia. This project is a significant step toward understanding the prevalence of cerebral palsy across diverse communities.

A Significant Step in Determining Prevalence

Gillette's partnership with the UMN ADDM site reflects our strong commitment to improving care for children who have cerebral palsy. The Gillette Cerebral Palsy Institute is one of the largest centers for cerebral palsy care globally, serving over 4,000 children annually.

While Minnesota has long been an ADDM site for autism research, this year marks

the pilot effort for cerebral palsy surveillance within the ADDM Network. The CDC will use this pilot year to refine methods for tracking cerebral palsy across all five sites. A key goal of this project is to gather critical information on cerebral palsy prevalence to better serve affected communities.

What's Next?

Gillette and UMN have completed uploading all patient surveillance data for CDC review. The CDC will summarize findings across participating sites and work to streamline data collection processes for future years.

"Many discussions will take place over the next few months regarding best practices for classifying and summarizing these complex data," says Dr. Burkitt. "Our aim is to ensure the highest quality information is available moving forward."



Chantel Burkitt, PhD



Meghan Munger, PhD, MPH

Learn more about other ways Gillette is improving cerebral palsy care at: gillettechildrens.org/research.

Gillette Children's Genetic Counselors

Gillette Children's is proud to have three genetic counselors on staff, along with access to geneticists from the University of Minnesota. This team helps more families uncover answers about rare diseases and complex conditions.

Spine Institute Earns Pediatric Spine Center Certification

We are proud to announce that Gillette Children's Spine Institute has achieved the prestigious DNV Advanced Pediatric Spine Certification. This recognition reflects our unwavering commitment to providing exceptional care and maintaining the safest healthcare environment for our patients.

Gillette Children's is the second hospital — and the first specialty hospital — in the nation to earn this certification. The DNV Advanced Pediatric Spine Certification framework is part of an established quality management system (QMS). The certification is supported by guidance from the Scoliosis Research Society (SRS), Pediatric Orthopaedic Society of North America (POSNA), American Academy of Orthopaedic Surgeons (AAOS), American Association of Neurological Surgeons (AANS), and other relevant agencies and organizations, including CMS and ASA.

"Earning this important designation reflects our dedication to delivering exceptional patient care and safety," says **Tenner Guillaume, MD**, co-chair of Gillette Children's Spine Institute. "It also underscores the commitment of our staff to continuously improving patient outcomes and ensuring the highest standards of care."



Tenner Guillaume, MD

Highlights from the Certification Process

The DNV surveyors reviewed quality data, patient charts, policies, and procedures, as well as interviewed patients and staff. During their evaluation, they commended Gillette for its:

- Comprehensive documentation
- Multidisciplinary team approach
- Staff engagement
- Positive patient and family feedback
- Organizational commitment to quality and evidence-based practices
- Data visualization and dashboards
- Thoughtful staff education plan tailored by role and topic
- Impressive research efforts and contributions

Looking Ahead

Gillette Children's Spine Institute is committed to building on this certification by implementing further process improvements, updating documents to reflect best practices, enhancing data capabilities, and advancing its staff spine education plan over the next year.

About DNV

DNV is a global leader in independent certification, assurance, and risk management. With deep expertise and broad experience, DNV advances safety and sustainable performance, sets industry benchmarks, and drives innovative solutions.

Michael Healy, MD, Named Chief Medical Director of Orthopedics



Michael Healy, MD

Gillette Children's is proud to announce the appointment of

Michael Healy, MD, as the Chief Medical Director of Orthopedics. Dr. Healy succeeds **Walter Truong, MD**, who has served as interim Chief and will now assume the role of Associate Medical Director of Orthopedics.

Dr. Healy is a Gillette fellowship graduate who completed his residency at the University of Connecticut and earned his medical degree at the University of Minnesota. Since joining Gillette as a staff orthopedic surgeon in 2009, Dr. Healy has demonstrated exceptional leadership, serving in roles such as Associate Medical Director of Surgical Services, Chief of Staff, NSQIP Pediatric CSV Surgeon Champion, and Program Lead for Joint Preservation. Additionally, he is actively involved in leadership within the American Academy of Cerebral Palsy and Developmental Medicine.

Dr. Truong, who joined Gillette in 2011, earned his medical degree from Ohio State University and completed his residency at the University of Minnesota, followed by a



Walter Truong, MD

fellowship at the Hospital for Sick Children in Toronto. He has served as Site Director for the Orthopedics Residents at Gillette and sits on the Board of Directors for CORTICES. Dr. Truong has received numerous research grants to advance care for Gillette patients and was recently selected for the prestigious POSNA/EPOS Traveling Fellowship.



1



2



3

1 Emily Bryant Kirschenblatt, MS, LCGC

2 Kayla Radle, MS, CGC

3 Kali Schreiner, MS, CGC

These efforts reflect Gillette's commitment to expanding access to genetic and genomic services. With this growth, the team is advancing care offerings for rare diseases and enabling new opportunities in clinical and translational research.

Gillette Children's Specialty Center Open Now!

New \$7 million specialty center renovation supports clinical collaboration for innovative research with three new lab spaces

Putting patients first and prioritizing welcoming aesthetics, designing Gillette Children's Specialty Center was a collaborative effort. The plans and layout were created based on feedback primarily from patients and families, many staff members from all outpatient service areas, the Gillette Family Advisory Council, and other community members.

The center's fifth floor is equipped with patient-focused enhancements like adult-sized changing tables in the bathrooms that shift in height for easy access from a wheelchair, a sensory wall, and color-changing, dimmable lights. It includes 12 exam rooms, a drop-in computer room, multiple outpatient pediatric psychological therapy and recreation rooms, play spaces, lactation areas, and last but certainly not least, three dedicated research labs with customized equipment storage.

The three different types of clinical labs — a collaborative research lab, a research wet lab, and a neuromodulation lab — offer seamless connections for physicians and their young patients enrolled in clinical trials for new devices, completing blood work, and undergoing cutting-edge care in brain and spinal therapies.

U.S. Rep. Betty McCollum was instrumental in securing \$1.5 million in federal spending toward the research labs. These include a hydraulic ceiling lift and cameras to help determine the pain levels of patients who are nonverbal, among other tools to assess motor control and movement disorders. The goal is to develop the latest equipment for children's specialty care, including biofeedback, robotic, and exoskeleton devices.

Moving concepts from research to clinical practice can take 17 years or more — in other words, an entire childhood — a frustration to medical experts like **Jennifer Laine, MD**, orthopedic surgeon and Medical Director of Research at Gillette Children's. Lining up patients, practitioners, and sizable new laboratories directly across the hall from each other will hopefully speed up that process while improving patient care.

"It's really about increasing efficiency, having a better quality of the space ... and it will really enhance patient and family inclusion," said Dr. Laine. "We think that it's really important that the research we do here is clinically relevant to our patients and families."

Gillette Children's Specialty Center space offers:

- State-of-the-art outpatient exam and treatment rooms
- Rooms and support space to enhance and advance patient-facing research initiatives
- Expanded psychology and psychotherapy treatment areas
- Therapeutic Recreation and play therapy rooms
- Space for Gillette employees to collaborate

Watch a Video Tour of the Specialty Center



Emilee Lund, 29, poses in front of an acrylic drawing she created for the new Gillette Children's Specialty Center on the fifth floor of the hospital in St. Paul, MN. Lund has been receiving services at Gillette since moving to the Twin Cities for art school 10 years ago.



An Infusion of Hope for Duchenne Muscular Dystrophy

How gene therapy Elevidys transforms lives amid risks, challenges, and new frontiers

Kim Thompson is feeling anxiety, gratitude, and many other emotions as she sits in the infusion room at Gillette Children's. Her older son, Caleb, 9, is about to receive an infusion of Elevidys, a new treatment recently approved by the Food and Drug Administration (FDA) for Duchenne Muscular Dystrophy (DMD).

DMD causes progressive muscle loss and weakness. Eventually this leads to serious medical problems with the heart and lungs. Many people who have DMD die in their 30s or 40s. The condition mostly affects males and is caused by a gene on the X chromosome mutating and failing to produce enough of the muscle-protecting protein dystrophin.

Elevidys is a gene therapy treatment for DMD manufactured by Serapta Therapeutics. It is delivered into the body via a single

Kim Thompson sits in the infusion room at Gillette Children's, with her son Caleb, who begins his Elevidys treatment for Duchenne Muscular Dystrophy.



Caleb is carefully monitored during the infusion process and will continue to be monitored for several hours after he receives the Elevidys to make sure he's tolerating it well.

intravenous (IV) infusion. At an estimated cost of \$3 million for a one-time, single-dose intravenous infusion, Elevidys is known as one of the most expensive drugs in the world.

Elevidys works by inserting an artificially produced gene called “microdystrophin” into muscle cells, which serves a similar purpose as dystrophin. Like many genetic drugs, the most challenging issue is safely getting the microdystrophin gene into the muscle cells. This gene is safely inserted using a vector called adeno-associated virus rh74 (AAVrh74). The AAVrh74 vector is nonpathogenic (or non-disease-causing), has been modified to be nonreplicating, and contains only the microdystrophin gene — not its own DNA. ELEVIDYS refers to the combination of the modified AAVrh74 vector and the microdystrophin gene that it contains.

The drug incorporates the AAVrh74 virus, but approximately 1 in 5 DMD patients are already immune to this virus. Unfortunately, those patients with immunity are not able to receive the drug. However, parents of eligible children diagnosed with DMD, see Elevidys as a breakthrough to help their child deal with this serious genetic neuromuscular disorder.

FDA Approval for Elevidys

In June 2023, the FDA granted accelerated approval for Elevidys to 4- and 5-year-olds without other disqualifying conditions based on clinical trials.

The FDA's decision to approve the treatment for a small number of DMD patients was initially a mixed blessing for the Thompson family, who live on a farm in the small, central Minnesota town of Verndale.

The FDA's approval meant that Thompson's younger son, Dawson, who is also diagnosed with DMD, would be eligible to be among the first patients to receive Elevidys because of his

Signs and symptoms of DMD by age

The signs and symptoms of DMD change as a child ages, so the progression of the condition is divided into stages. Of course, the symptoms associated with each stage of DMD overlap and differ for each child. DMD is usually diagnosed when the child is between ages 2 and 7. Often, delays in early milestones — such as walking — are the first evidence of the condition.



Infants to Preschoolers (0 to 5 Years)

Children in this age range who have DMD might:

- Move more slowly
- Have trouble speaking
- Have learning or behavior problems
- Fall frequently
- Get tired easily
- Have fibrosis of the muscles. Fibrosis occurs when scar tissue replaces damaged muscles, causing joint tightness



School Age (6 to 10 Years)

Children in this age range who have DMD might:

- Start experiencing weakened arms, hands, and thigh muscles (called quadriceps)
- Have difficulty walking, or shift their weight when walking
- Need a stroller, scooter, or manual wheelchair for longer distances
- Get tired easily



Preteens and Younger Teens (11 to 15 Years)

Children in this age range who have DMD might:

- Not be able to walk
- Need to use a power wheelchair
- Be at risk for developing scoliosis
- Experience additional weakness in the arms and hands



Older Teens and Adults (16 and Older)

Teens and adults in this age range who have DMD:

- Will likely need a power wheelchair
- Might have some remaining function in their hands
- Often have difficulty maintaining good posture
- Might have difficulty breathing and need to use a respirator

age and the fact that he was still able to walk. Kim says knowing one of her sons would get the new treatment while her older son would have to wait on the sidelines was agonizing.

“It was a hard decision to let Dawson get the infusion,” Kim recalls. “We felt conflicted because Caleb was initially too old



Dawson, living with DMD, is one of the first patients to receive Elevidys due to his age and ability to walk.



Jamie Eskuri, MD



Randal Richardson, MD

Jamie Eskuri, MD, and Randal Richardson, MD, both provide care for Duchenne Muscular Dystrophy and other neuromuscular conditions at Gillette. They were thrilled to be able to offer this life-changing gene therapy treatment to more than 90 qualified Gillette patients in 2024.

care pediatrician, a cardiologist, Dr. Eskuri, members of the Gillette neurology team, several nurses, and other specialists.

Elsewhere at Gillette, the pharmacy team was defrosting 32 vials of Elevidys, so they could transfer the medication into 7 syringes that would get infused into Caleb's arm. Though Elevidys is a one-time treatment delivered via IV infusion, it's a relatively high dosage of 1.33×10^{14} vector genomes to ensure enough muscle cells are treated. Although the AAVrh74 vector is not disease-causing, it is similar to the AAVrh74 virus, so the immune system responds to the vector and its components as it does with any virus or foreign body.

The amount of drug given can cause immune system hyperactivation, which means some patients experience nausea, vomiting, and fever in the first week after an infusion (more than half of patients). As the vector selectively attaches to muscle tissues and is excreted in the stool, side effects like inflammation in the liver (acute serious liver injury, ~1 in 3 patients), skeletal muscles (immune-mediated myositis, ~1 in 100 patients), and heart (myocarditis, ~1 in 100 patients) have also been reported.

A Strong Parent and Provider Partnership

"I'm pleased both Caleb and Dawson received the Elevidys infusion," Dr. Eskuri says. "The Thompsons have done everything right for their sons and have been incredible through this journey."

As a pediatric neurologist, Dr. Eskuri is at the forefront of a new area of medicine. The past 10 years have brought significant research and change for several serious childhood conditions. The Gillette neurology team is a pioneer in the use of Spinraza and Zolgensma, two treatments for spinal muscular atrophy (SMA). Gillette is also a Muscular Dystrophy Association Care Center.

The Minnesota Department of Health recognizes Gillette's leadership in these new treatments and has sought the expertise of Dr. Eskuri and pediatric neurologist Randal Richardson, MD.

"Dr. Richardson and I have been invited to be on a Minnesota Department of Health task force to set up guidelines and procedures for newborn screening for DMD," says Dr. Eskuri. "Because of Elevidys and other possible new treatments, it's important to get babies screened as soon as possible, evaluated as soon as symptoms occur, and to provide much-needed treatment options for families."

For the FDA window to get Elevidys. How could we tell Caleb that his brother was getting this new treatment, and he could not?"

Infusion Day Arrives, Requires Frequent Monitoring

Shortly after Dawson's Elevidys infusion in March of 2024, Jamie Eskuri, MD, called the Thompsons to report the FDA expanded access to Elevidys and that insurance approved the treatment for Caleb. After months of medical preparations and blood tests, Caleb's big day finally arrived in September 2024.

It was a long day for the Thompsons as many Gillette specialists checked and double-checked to make sure Caleb was ready to receive the Elevidys infusion. Caleb was examined by a complex



Gillette Children's Welcomes First Vice President of Research

Advancing innovative care for children with complex conditions through collaboration, expertise, and family engagement

In a significant step toward expanding its leadership in specialty healthcare, research, and innovation, Gillette Children's is proud to welcome **Coen Wijdicks, PhD, MBA**, as its First Vice President of Research. Through this pivotal role, Dr. Wijdicks will shape Gillette's strategic research vision, oversee research operations, and lead efforts to promote the dissemination and implementation of cutting-edge research.

"I am honored to join Gillette Children's and work alongside such a talented and passionate team," said Dr. Wijdicks. "I look forward to building on Gillette's exceptional foundation of research and innovation to make an even greater impact on the lives of children and families worldwide."

Dr. Wijdicks brings extensive expertise from both academia and industry. Most recently, he served as Senior Director of Global Research at Arthrex Inc. — a global leader in multispecialty minimally invasive products and surgical techniques — where he led a multidisciplinary team excelling in clinical research, biomechanical testing, biomaterials research, and biomedical engineering. His leadership expanded impactful collaborations with academic institutions and professional societies. Dr. Wijdicks holds an Executive MBA from the Quantic School of Business and Technology, a PhD in Biomedical Science from the University of Oslo, an MS in Anatomy and Cell Biology from Rush University, and a BS in Biological Science from Colorado State University.

In this new role, Dr. Wijdicks will work in close collaboration with Jennifer Laine, MD, Gillette's Medical Director of Research. As dyad partners, they will drive evidence-informed clinical care advancements and ensure Gillette's research programs align



Coen Wijdicks, PhD, MBA



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seamlessly with the organization's clinical strengths and mission, improving the lives of patients worldwide.

"Our research efforts are guided by the desire to transform patient care through evidence and innovation," said Dr. Laine. "I am thrilled to partner with Dr. Wijdicks, whose expertise and vision will elevate our work to new heights, making a profound difference in the field of pediatric specialty care."

Research and Innovation at Gillette

Research is foundational to enhancing care for children with brain, bone, and movement conditions. Gillette's research department consists of eight specialized programs, each led by dyad co-directors — a clinical scientist paired with a physician — who oversee studies in their area of expertise.

This collaborative structure ensures that research efforts not only advance medical knowledge but also translate discoveries into tangible treatments and therapies that will directly impact care for patients at Gillette and throughout the world.

Family Engagement in Research Center's Lived Experience

Gillette remains committed to the Family Engagement in Research approach, which integrates Lived Experience Partners into the research process. This unique model emphasizes the collaboration of researchers, clinicians, and individuals with lived experience to design, conduct, and apply research that is both clinically relevant and personally meaningful. By combining scientific expertise, compassionate care, and real-life insights, Gillette is producing impactful research that enhances the quality and value of our studies.

Gillette research programs and dyad co-directors include:

Pain and Comfort	Spine	Rehabilitation	Health Services
Chantel Burkitt, PhD	Sara Morgan, PhD	Alyssa Spomer, PhD	Rhonda Cady, PhD
Todd Dalberg, MD	Dan Miller, MD	Linda Krach, MD	Tori Bahr, MD
Orthopedics	Gait and Motion Analysis	Neurosciences	Cerebral Palsy
Susan Novotny, PhD	Andy Ries, PhD	Mo Chen, PhD	Liz Boyer, PhD
Jennifer Laine, MD	Tom Novacheck, MD	Peter Kim, MD	Andrea Bushaw, PhD
			Tom Novacheck, MD

Recent Research Highlights
 With more than 75 studies published in 2024, Gillette research teams continue to make advancements in treating childhood-onset disabilities.

Down Syndrome Clinic Fills Community Gap



Care and support from childhood through adulthood

Gillette Children's is proud to announce the launch of its new Down Syndrome Clinic. Staffed by Complex Care providers **Tori Bahr, MD, Heidi Davis, NP, Peter Ladner, MD, and Uyen Truong, MD**, in collaboration with the Down Syndrome Association of Minnesota (DSAMN), this clinic now offers collaborative, multidisciplinary care appointments for patients who have Down syndrome beginning at birth.

Meeting a Critical Need

Despite a steady number of children born with Down syndrome in Minnesota and western Wisconsin each year, local care options have been limited, especially as they age into adulthood. This new clinic addresses the need for comprehensive medical care planning and access to community resources from birth through the transition to adulthood. Our DSAMN partnership enhances this vital support.

Why Refer Patients to Gillette

- **Comprehensive Care:** Gillette Children's is a regional leader in genetic syndrome care, offering extensive medical, surgical, and rehabilitation services
- **Expanded Age Range:** Appointments available from birth to age 25
- **Dedicated Support:** A registered nurse care manager oversees all care needs and appointments
- **Embedded DSAMN:** The DSAMN collaborates directly in our clinic, connecting patients to community resources
- **Quick Care Clinic:** Available Monday–Friday for acute illnesses in established Gillette patients, staffed by providers
- **Transition Support:** Assistance for patients transitioning from pediatric to adult healthcare

Common Healthcare Needs

Gillette addresses the needs of those who have Down syndrome, including:

- **Hearing and Speech:** Regular auditory exams and speech therapy.
 - **Sleep Apnea:** Care, including sleep studies and interventions like ENT evaluations, CPAP therapy, or Inspire (hypoglossal nerve stimulator) devices
 - **Acute Illness Concerns:** Increased susceptibility to infections requires vigilant care. The Gillette Quick Care Clinic ensures minor concerns don't escalate
 - **Joint Laxity and Hypotonia:** Multidisciplinary care from orthopedics, PM&R, and neurosurgery teams for musculoskeletal and atlanto-axial concerns
 - **Developmental Support:** Early gross motor intervention programs and support for developmental challenges
- The launch of this clinic represents a significant enhancement in the support and care available to individuals with Down syndrome and their families

Collaborate with Us

We welcome collaboration on complex Down syndrome cases. Here's how to start:

- **Contact Us:** Call us at **651-325-2200** or visit **gillettechildrens.org/referral**. Provide a brief overview of the case and the patient's specific needs
- **Case Review:** Our team will review medical records, assessments, etc.
- **Appointment:** We'll schedule a comprehensive evaluation to create a tailored care plan with input from specialists like ENT, sleep medicine, and DSAMN
- **Ongoing Communication:** A registered nurse care manager coordinates all aspects of care to keep you updated
- **Follow-Up:** Regular appointments will monitor progress and refine the care plan as needed
- **Learn more:** **gillette.mn/ds-care**

Meet the Down Syndrome Clinic Providers

Tori Bahr, MD, FAAP

Internal Medicine and Pediatric Physician, Medical Director, Pediatrics

Residency: University of Minnesota Medical Center – Internal Medicine and Pediatrics Program

Board Certifications: American Board of Pediatrics, American Board of Internal Medicine

Specialties: Pediatrics, General Medicine, Complex Care



Heidi Davis, APRN, CPNP

Pediatric Nurse Practitioner

Education & Training: University of St. Catherine, St. Paul, MN – Master of Arts in Nursing

Board Certifications: Pediatric Nursing Certification Board

Specialties: Pediatrics, General Medicine, Complex Care



Peter Ladner, MD

Internal Medicine and Pediatric Physician

Residency: University of Minnesota Medical Center – Internal Medicine and Pediatrics Program

Fellowship: University of Chicago Pritzker School of Medicine – Pritzker Research Fellowship

Specialties: Pediatrics, General Medicine, Complex Care



Uyen Truong, MD

Complex Care Pediatrician

Residency: University of Texas at Austin Dell Medical School – Pediatrics

Board Certifications: American Board of Pediatrics

Specialties: Pediatrics, General Medicine, Complex Care



Complex Care: A Guide for Referrals

In his Complex Care appointment, Matthew Hendrick and his mom meet with Dr. Uyen Truong and discuss support for his rare disease.

Gillette Children's Complex Care team supports families at every step

The Complex Care team at Gillette Children's provides expert disability care, care management, and care navigation services for patients from birth to age 26. Led by **Tori Bahr, MD**, Medical Director of Pediatrics at Gillette, the team collaborates with primary care providers, subspecialty physicians, and families to deliver services that are both comprehensive and convenient.

Who Should Be Referred to Gillette's Complex Care Team?

The Complex Care team serves children, teens, and young adults (from birth to age 26) who have multiple chronic health conditions or complex medical needs, including neurodevelopmental disabilities or technology dependencies. At Gillette Children's, Complex Care takes a multidisciplinary approach, focusing on the patient's social, mental, and physical well-being.

Common issues addressed at the Complex Care Clinic include:

- Management and coordination of care
- Chronic care needs

- Disability-specific preventive care needs
- Feeding and nutritional support (e.g., FTT, G-tube, J-tube)
- Ketogenic diet management
- Transition to adulthood planning
- Aspiration and drooling

Our team collaborates with specialists within and outside Gillette and works closely with patients' primary care providers to ensure seamless care coordination. We prioritize patient-centered care that meets the unique needs and goals of each individual and their family.

Signs a Patient May Benefit from Complex Care Services

Patients who exhibit the following may benefit from a referral to Complex Care:

- High care coordination needs
- Frequent illnesses or hospitalizations
- Feeding or medication concerns
- Caregiver burnout

Partnering With You

We're excited to collaborate with you in the care of your complex pediatric patients.

After meeting with your patient to discuss their goals and concerns, we create a comprehensive, multidisciplinary care plan tailored to their needs. This plan includes input from relevant Gillette specialists and focuses on delivering high-quality, personalized care.

You Can Expect:

- Ongoing communication with our team to co-manage care and address emerging issues
- Coordination of all aspects of care by our registered nurse care managers.
- Updates on progress and any changes to the care plan
- Regular follow-ups to monitor progress and adjust care as needed

How to Refer

To refer a patient, call **651-325-2200** or visit gillettechildrens.org/referral. Please provide a brief overview of the case, specific concerns or needs, and the best contact information for your care team.

A Denial, Then a Diagnosis

Expertise and innovations provide lifelines for families like the Thompsons

Kim and Rick Thompson began bringing their sons, Caleb and Dawson, to Gillette Children's in 2021 after genetic testing confirmed what they feared — Caleb had Duchenne muscular dystrophy (DMD).

"I was in denial," Kim confesses. "I saw that Caleb had issues walking and climbing stairs. In my mind, I feared it was DMD but hoped it might be something else."

DMD was on Kim's radar because her brother was diagnosed with the disease. She grew up seeing its devastating effects. Sadly, her brother died from DMD at the age of 20.

The Thompsons' first visit with Gillette pediatric neurologist **Jamie Eskuri, MD**, gave them the support and education they needed. Once Caleb received his official diagnosis for DMD, Dawson was tested, and the family realized both boys had DMD.

"Right away, we got along with Dr. Eskuri," Kim recalls. "She was literally the first provider we saw at Gillette, and she

told us to have hope. She said there were new treatments being developed and that Gillette was one of the places in the loop for these new tools."

"Grab Any Lifejacket Offered"

In early 2024, Dr. Eskuri called the Thompsons with the news that Dawson was eligible to be one of the first children to receive the Elevidys infusion.

"Dr. Eskuri told us about all of the side effects, which include possible liver and heart damage," Kim says. "She also told us about the long process involved in making sure Dawson's body was prepared to receive the infusion and the possible issues we might have with our insurance company to get approval for this expensive treatment."

Kim acknowledges it was a scary time for her family, saying, "I shared our concerns with Dr. Eskuri. She understood our reluctance but advised us to 'grab any lifejacket offered.'"

Shortly after Dawson's Elevidys infusion in March 2024, the FDA expanded access to Elevidys, and the Thompsons' insurance approved the treatment for Caleb.

A Hopeful Future and Strong Results

Kim Thompson wants other families dealing with a diagnosis of DMD to hang on to hope. A few weeks after Caleb's infusion, Kim reports, "Caleb and Dawson are doing great!"

She says neither boy has had any negative side effects from the Elevidys infusion. The Thompsons are very pleased with what Gillette and the Elevidys infusion have meant to their sons.

"I'm hoping this treatment will allow the boys to stay strong, at least throughout the rest of their childhood, and to be able to run around and just be kids," Kim says. "I hope someday a cure for this awful disease will be found so no one else has to go through it."

Kim Thompson shares hope for families facing DMD, as sons Caleb and Dawson thrive after their Elevidys infusion with no negative side effects.





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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-55577

Voices of Our Families

Heartfelt shout-outs from our patient families

Each month, we receive a ton of positive feedback from patient families regarding their care experiences. Below are some shout-outs our providers recently received.

"We love Gillette and all the staff. We are always so pleased with our son's care. Dr. Dahl and his colleagues, as well as the nursing staff, are so good at what they do. Everyone was friendly, smart and on time. We are lucky to have access to such great medical care. Thank you to everyone!"

"We love Dr. Guillaume! He's so sweet and really shows care for his patients. So happy he's our care provider!"

"We always have a lot of different appointments when we come in, but we were only at the clinic for three hours — met with Dr. Schuh, had X-rays, got a new splint, got the wheelchair serviced, and were fitted for a new AFO."

"We love Dr. Gettings. She makes us feel like we are a team and friends. We work together to do what is best for our child."

"Analise Ludwig and every staff member we met or passed in the hallway were all so kind. We saw many smiling faces and felt welcomed for our first visit with Gillette Children's. Analise was genuinely kind and supportive. My son's appointment was on Halloween, so we were able to participate in trick-or-treating at the facility, and it was such a heartwarming experience. We are blown away by the first experience we had!"



Mark Dahl, MD, Pediatric Orthopedic Surgeon



Tenner Guillaume, MD, Pediatric Orthopedic Spine Surgeon



Lee Yung Schuh, MD, Rehabilitation Medicine Physician



Jill Gettings, MD, Rehabilitation Medicine Physician, Medical Director Adult Medicine



Analise Ludwig, AUD, CCC-A, FAAA Audiologist