

gillette

Partners in Care

JOURNAL

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SPRING 2024



A Strong Start

Gillette's Infant and
Toddler Evaluation offers
early treatment for
developmental delay

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On the cover: Ernesto Prieto works toward his movement goals with his occupational therapist.

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About Our Journal

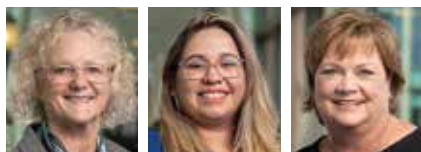
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Gillette CME Program Achieves Accreditation

Gillette's CME Program was surveyed by the Minnesota Medical Association and subsequently awarded accredited status, as a continuing medical education (CME) provider, through 2027.



This accreditation allows Gillette to continue to provide high-quality and impactful educational activities to meet the educational needs of our clinicians at Gillette and external clinicians who serve our patient population.

In addition to serving our medical staff, our CME Program remains dedicated to the development of educational programming that continues to support the organization's strategic focus along with our vision, mission, and values.

Did you know?

Pediatric Section Chief **Tori Bahr, MD**, is a 2024 Minneapolis/St. Paul Business Journal (MSPBJ) 40 Under 40 winner.

The magazine's annual honor recognizes Dr. Bahr's passion for caring for children with special needs and leadership in creating a better healthcare system for these patients as they become adults.

The editorial team at MSPBJ selected 40 local leaders — from hundreds of nominations — who are under the age of 40, recognizing their professional accomplishments, community involvement, and industry leadership.

Dr. Bahr is well known for her advocacy of focusing on transition care for patients with special needs. Today she is using her expertise to lead this work in many ways:

- She co-leads Gillette's Transition Task Force and Transition Initiatives, active multidisciplinary groups seeking to transform the care provided to Gillette patients.
- She created a transition clinic within the complex care clinic at Gillette to support individual patients in finding a comprehensive, effective healthcare team.
- At the University of Minnesota, she created a transition workshop and leads education days for medical residents, including the Internal Medicine, MedPeds, and Pediatric programs.
- She created a Twin Cities Inpatient Transition QI Group and is a medical advisor and facilitator for the Disabled Not Disposable: A Health Equity CME (Continuing Medical Education) Conference.
- She co-leads the Gillette's Children and Youth with Special Health Needs Health Care Transition Learning Collaborative, a groundbreaking project supported by a \$160,000 grant from the Minnesota Department of Health and a \$50,000 grant from the COPIC Medical Foundation.



Welcome New Gillette Staff!

We're happy to introduce our new team members



Kelsey Everson, APRN, CPNP, has joined Gillette Children's as a pediatric nurse practitioner on the Craniofacial and Plastic Surgery team. She specializes in conditions such as craniosynostosis, plagiocephaly, cleft lip and palate, and more.

Everson received her Master of Science in Nursing at the University of Rochester School of Nursing. She is board certified by the Pediatric Nursing Certification Board and is also a member of the National Association of Pediatric Nurse Practitioners (NAPNP).

"I love working with infants and children. I enjoy helping families through their own unique healthcare journey and watching the patients I work with grow and thrive," Everson says. "I want to educate patients and caregivers to help take the fear/mystery out of healthcare so they can continue to be their own best advocate."

As a leader in craniofacial and plastic surgery, Gillette Children's provides access to leading craniofacial surgeons paired with the latest surgical techniques and technology for kids who have complex conditions. Whether treatment begins in infancy or early childhood, our goal is to improve a child's physical appearance and promote self-confidence.

John Fox, DO, has joined Gillette Children's as a physical medicine and rehabilitation physician. Dr. Fox is board certified in physical medicine and rehabilitation, and pediatric rehabilitation medicine by the American Board of Physical Medicine and Rehabilitation. He specializes in treating conditions such as cerebral palsy, spina bifida, Rett syndrome, brain injury, and more.

Dr. Fox received his Doctor of Osteopathic Medicine at Lake Erie College of Osteopathic Medicine before completing his residency in physical medicine and rehabilitation at Rusk Rehabilitation, New York University. After finishing his fellowship in pediatric rehabilitation medicine at the University of Minnesota and Gillette Children's, Dr. Fox is excited to be back at Gillette seeing patients at locations in St. Paul, Maple Grove, and Burnsville.

"I enjoy Physical Medicine and Rehabilitation because it allows me to work with a collaborative team to focus on improving function and quality of life for our patients," Dr. Fox says. "My training and experience in both pediatric

and adult rehabilitation medicine care provides me with a unique perspective to aid in the transition of patients with childhood onset disability into adulthood. My aim is to provide holistic, patient-centered care and education to help patients meet their rehabilitation goals."

Gillette Children's has the highest concentration of pediatric rehabilitation medicine specialists in the nation. It is one of three pediatric specialty programs in Minnesota accredited by the Commission on the Accreditation of Rehabilitation Facilities (CARF) to meet the needs of young children and adolescents seeking acute inpatient rehabilitation. Gillette is one of eight US pediatric inpatient rehabilitation facilities to have CARF accreditation for both its pediatric specialty and pediatric brain injury programs.

With both pediatric and adult-focused providers, Gillette supports families in making the transition to adult-focused healthcare.



Peter Ladner, MD, has joined Gillette Children's as an internal medicine and pediatric physician. He specializes in treating developmental delays and conditions such as cerebral palsy, brain injury, Down syndrome, genetic conditions, and more.

Dr. Ladner attended medical school at the University of Chicago Pritzker School of Medicine before completing his residency in pediatrics at the University of Minnesota. Dr. Ladner is excited to now be seeing patients at Gillette locations in St. Paul and Maple Grove.

"As an internist and pediatrician, I aim to help patients and families manage complex medical conditions while navigating changes in health from childhood through adulthood," Dr. Ladner says. "I strive to be an advocate for my patients' individual needs and goals. Given my background in both internal medicine and pediatrics, I am especially interested in how I can help smooth the transition from pediatric to adult medical care for my patients."

The Pediatricians and General Medicine practitioners at Gillette Children's have deep expertise working with children who have disabilities, and adults who have complex conditions that began in childhood.



Renewed Hope for Gillette Rett Syndrome Patients

There are promising improvements for patients diagnosed with Rett syndrome one year after the FDA approved Daybue (trofinetide) as the first treatment to help people with the rare neurodevelopmental disorder.

About 50 Gillette Children's patients diagnosed with Rett syndrome have been taking Daybue for about a year.

"These patients are improving incrementally, and we see improvements in communication skills, breathing, and overall quality of life," says **Arthur Beisang, MD**, co-director of the Gillette Children's Rett Syndrome Center of Excellence.

Gillette is one of 18 institutions in the US designated as a Center of Excellence by the International Rett Syndrome Foundation (IRSF). Dr. Beisang and pediatric neurologist **Tim Feyma, MD**, co-direct the Gillette Children's Rett Syndrome Center of Excellence.

"Gillette really became a center of excellence because parents of kids who have Rett came to us and said, 'We need a voice in the medical field.' It is really the parents and the Gillette leaders who helped us become a strong place for rare disease care," Dr. Feyma says.

Gillette is instrumental in the trials and approval of Daybue

Gillette Children's worked with the drug's manufacturers, Acadian Pharmaceuticals and Neuren Pharmaceuticals, for the past 11 years and had several patients enrolled in the clinical trial of Daybue. Drs. Beisang and Feyma were investigators in the clinical trials of the drug, which helps increase the connections between neurons and makes nerves more robust.

"The trials for Daybue started back in 2013," Dr. Feyma recalls. "After a mountain of paperwork and hard work from our providers, research coordinators, pharmacists, prior authorization team, and others, we have progress and can offer Daybue as an option."

Drs. Beisang and Feyma are pleased there is now hope and a treatment is for Rett syndrome patients, and both say this progress is the result of many years of hard work and the dedication of parents. They also stress Daybue is a treatment for Rett and not a cure.

"We consider Daybue to be the first therapy success for Rett, but it won't be the last," Dr. Beisang says.

Gillette Children's Rehabilitation Research Program Names Director

Gillette Children's has appointed **Alyssa Spomer, PhD**, as co-director of the Gillette Rehabilitation Research Program. Dr. Spomer joins **Linda Krach, MD**, in providing scientific leadership for the program.



Alyssa Spomer, PhD



Linda Krach, MD

Some people who have physical disabilities, chronic pain, or serious injuries need help to develop or regain strength, pain relief, mobility, and independence. Rehabilitation services at Gillette Children's help these people restore their movement and functional abilities and enhance their quality of life.

The Gillette Rehabilitation Research Program is dedicated to understanding and improving rehabilitation strategies and outcomes for children with complex movement conditions. The active research priorities include developing and evaluating novel rehabilitation technology and interventions, advancing evidence on early detection and intervention in cerebral palsy, characterizing motor control and recovery following neuromuscular injury, and evaluating current standards of care.

As co-directors, Drs. Spomer and Krach will set the Rehabilitation Research Program's strategy, grow collaborative and productive clinical research teams, and support rigorous and meaningful research that will translate into clinical practice in rehabilitation services.

Drs. Spomer and Krach have a dedicated and creative team of collaborators across the organization to drive innovative research initiatives that will both positively contribute to the broader scientific community and advance the quality of care for Gillette patients.

Next Steps

Pediatric to Adult Healthcare Transition Initiative (Aptly) Prepares for the Future

After years of patient and family interviews, surveys, and focus groups calling for increased support in Healthcare Transition (HCT), Gillette formally kicked off a Pediatric to Adult Healthcare Transition Initiative in late 2023.

The initiative group, led by **Tori Bahr, MD**, and **Rhonda Cady, PhD**, consists of a multidisciplinary group of stakeholders from across Gillette — all of whom hope to impact the HCT services offered at Gillette in the future.

Why is healthcare transition so important?

Put simply, everyone ages! Currently, very few healthcare providers have a structured HCT process for pediatric patients with complex medical needs, their parents and caregivers, healthcare staff, and the support community. This lack results in unsafe, fragmented care and causes widespread quality, time, financial, and satisfaction implications.

Dr. Bahr says: "Gillette cares for a unique patient population with lifelong conditions. All our patients will need continued care as they age, which means all the pediatric care they receive must be transitioned. We can't provide comprehensive adult care for every patient, but we can ensure they are successful in this change to their care. The good news is we already have a lot of the resources needed at Gillette to do this important work!"

Beyond efforts within Gillette, external support further illustrates the hunger our community and families have for structured transition guidelines. For example, patients and families consistently ask for transition resources in the Community Health Needs Assessment (CHNA). "Our HCT work naturally builds off community projects like the **Health Care Transition Learning Collaborative** as well as national and statewide grants received at Gillette in the last four years," Dr. Cady says, "We've received an American Academy of Pediatrics Spina Bifida grant, a COPIC Medical Foundation grant, and two Minnesota Department of Health grants."

What is the goal of the Initiative?

The group's overarching mission is to provide Gillette with a comprehensive set of pediatric-to-adult HCT timelines, services, and resources for patients, families, caregivers, and their care teams both inside and outside of Gillette.

"My goal in this work is to continue to advocate for our responsibility to improve our patients' lives and to create a more inclusive and equitable healthcare transition process," Dr. Bahr says.



Tori Bahr, MD



Rhonda Cady, PhD



How can providers get involved with Healthcare Transition initiatives at Gillette?

Transition to adult care affects every patient. Collaborate and learn more about this important work:

- 1. Watch past sessions** and join the remaining monthly Health Care Transition Learning Collaborative education sessions.
- 2. Save the Date!** Attend the Health Care Transition Learning Collaborative Summit on June 13, 2024. Join this hybrid opportunity virtually or in person in St. Cloud, MN. Registration is open now. See page 12 or scan the QR code at right for more details.
- 3. Help inform your patients** about HCT by sharing resources like those found at gillettechildrens.org/transition-faqs.



Learn more about the Summit.

Dr. Bahr's Top Tip for Transition

We asked Dr. Bahr: If you could snap your fingers and have every pediatric provider immediately adhere to an HCT recommendation, what would that recommendation be and why?

"Instead of waiting until patients are 18, talk about healthcare transition with your patients early and often. Families can't prepare for what's to come without knowing what to expect!"



Family Engagement in Research

Gillette Children's Launches Family Engagement in Research Program

Gillette is excited to launch its Family Engagement in Research (FER) program. As one of just a handful of US research programs using FER, this program continues a tradition of innovation and builds on the organization's belief in the power of collaboration in research.

FER is a collaborative, best-practice approach that equally values contributions from lived experience partners (LEPs), clinicians, and researchers in all phases of the research process. By actively and equally engaging researchers, clinicians, and LEPs, we create groundbreaking and meaningful research that unites expertise, compassion, and real-life insights, increasing the quality and value of our studies.

The FER program at Gillette aims to create innovative, impactful, and inclusive research that supports the best possible outcomes and improves the quality of life for patients and families at Gillette and worldwide.

LEPs Integral to Success

LEPs are an essential part of the FER program at Gillette. LEPs are individuals, or primary caregivers of the individual, who have a musculoskeletal or neurological condition treated at Gillette. "Lived experience" refers to experience with special healthcare needs, especially the day-to-day tasks including appointment coordination, care team management, daily caregiving, navigating disability

"Our parent advisors are essential to all that we do. We have all learned so much over the last five years having them as a part of our clinic."

-Tori Bahr, MD, Internal Medicine and Pediatric Physician, Medical Director of Pediatrics at Gillette Children's



"Lived experience partners share experiences that are not always easy to hear but what we need to hear to improve."

-Gillette Children's Clinician

programs, insurance, and more, that occur outside clinic or hospital walls.

Training is required for all members of the team assuring LEPs are familiar with the research process and are informed partners. As part of FER, researchers and clinicians are trained in a new way of conducting research in collaboration with LEPs.

Many organizations that fund research through grants may require LEPs to be included in the project. For example, PCORI-funded grants currently require the use of LEPs. Many high-profile publications such as the NIH also encourage, recommend, or require the use of Lived Experience or Patient Partners in the research projects they publish or feature.

What value do LEPs bring to research?

The level of engagement, role, and expectations for LEPs are guided by the principal investigator for each research project. Engagement can range from attending meetings and giving advice to being an equal partner or final decision-maker.

LEPs provide critical and unique expertise about 'life outside the clinic walls' to all facets of research, allowing research teams to consider more perspectives and increase the impact of research results. Some examples are:

- Idea generation/research question refinement and/or prioritization
- Define/develop research grant proposal and/or research protocol
- Review documents for recruitment/study materials and provide feedback
- Interpretation/contextualization of results
- Disseminate research findings

Gillette's commitment to FER is built on the promise to provide exceptional healthcare to patients. By putting families at the center of not just clinical care and special projects, but research initiatives as well, Gillette can confidently offer meaningful recommendations and findings to improve care for all.



To learn more about implementing Lived Experience Partners at your organization, reach out to

providerrelations@gillettechildrens.com.

When Are Lived Experience Partners Engaged?

Lived Experience Partners (LEPs) can be engaged early in the research project to help co-create research questions and design the research project to be more meaningful to our population, but they can be added at any time.

Example 1:

A research team is having trouble getting patients to complete surveys.

Solution – Engaging LEPs can help identify questions that are more meaningful and pertinent to the participants, leading to a larger volume of patient responses.

Example 2:

Researchers are having trouble recruiting participants for the research study.

Solution – Engaging LEPs can help identify potential communication hurdles and co-develop a strategy for understanding the best times to approach participants and when they are most open to hearing about a research study.

Example 3:

Researchers suspect their focus groups aren't being forthcoming with their feedback.

Solution – Participants would be more honest if facilitation comes from someone who has experience with the condition instead of being scientist-led. LEP-led focus groups can help the conversation be more approachable and allow participants to feel more comfortable, in addition to narrowing a focus to what's most important to participants.



Putting Patient Needs First

Cerebral Palsy Care Coordination Pilot a Success

The Cerebral Palsy Care Coordination (CPCC) program is Gillette Children's first step toward a sustainable, replicable population healthcare model. After a nine-month pilot period filled with key lessons and insights, the program recently started sharing preliminary conclusions from its work with the first 147 patients.

Using expertise from literature, Cerebral Palsy Institute staff, and clinicians, Gillette compiled its Cerebral Palsy Care Guidelines. The CPCC program helps families to adhere to these guidelines, proactively identifying, addressing, and anticipating patient needs.

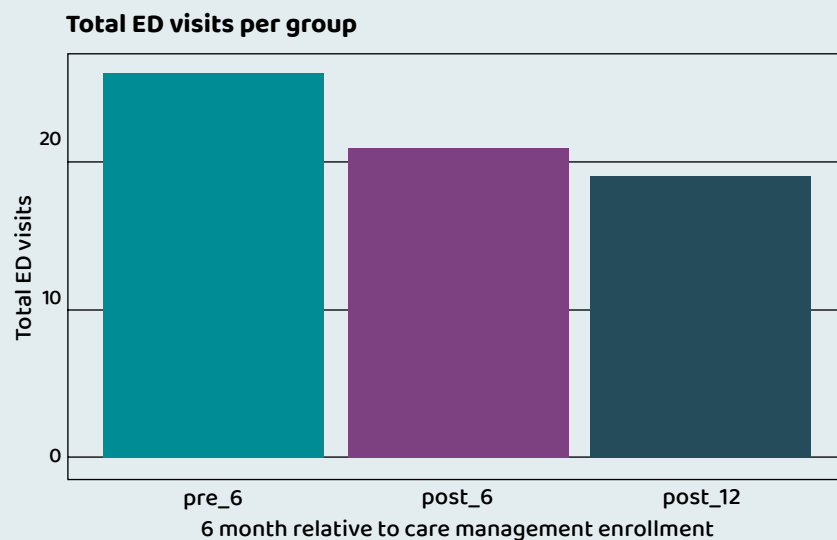
Gillette Cerebral Palsy Guidelines

Pilot guidelines determined by synthesized body of literature, Cerebral Palsy Institute workgroups, and clinical experts

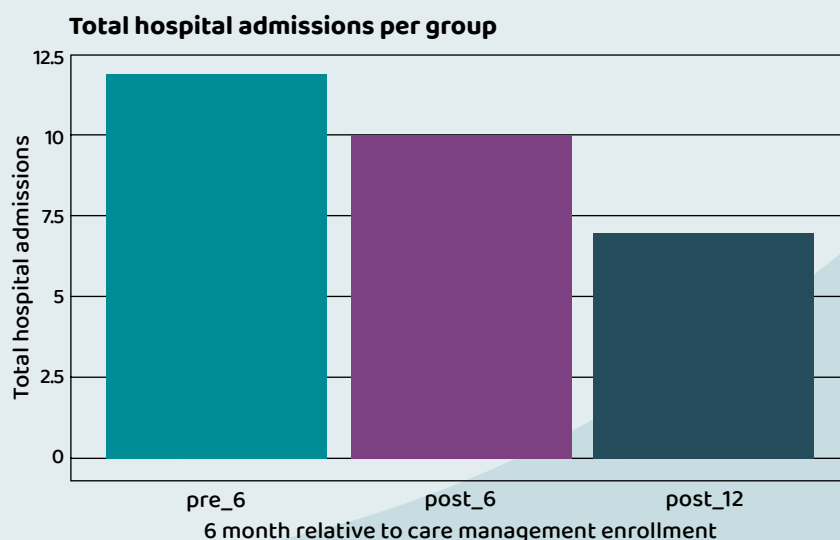
- Hip surveillance per American Academy for Cerebral Palsy and Developmental Medicine guidelines
- Established care and collaboration with a primary care provider
- Early intervention referral for children under 6 years old
- Neuropsychology testing completed by 7 years old
- Annual physical therapy, occupational therapy, and speech evaluations as indicated by physical medicine and rehabilitation (PM&R) provider
- Annual PM&R appointment
- Annual orthopedic evaluation (GMFCS II-V) as indicated by orthopedic provider
- Instrumented gait analysis by 5 years old and every three years until skeletal maturity (GMFCS I-III)*
- Upper extremity tone clinic by 7 years old (when applicable)
- Neurosurgery evaluation by 8 years old

*CP Guideline: stabilization of acute family need

Preliminary Results: Emergency Department Visits



Preliminary Results: Hospitalizations



Key Insights

The biggest conclusion from the CPCC pilot is that care coordination for patients who have complex medical needs like cerebral palsy (CP) is highly necessary — and it makes a difference. “We need care coordination at a population level because many of our patients and families have unmet needs that affect their daily lives, and we can catch these needs earlier with proactive support and monitoring,” says Kari Kubiatiowicz, director of Care Management at Gillette.

Upon enrollment, the group found 82% of patients were missing one or more CP Care Guidelines and 21 of 67 surveyed patients had one or more unmet medical needs within the past six months. The most common unmet medical needs were neuropsychology evaluation and having an active primary care provider, but other services were mentioned too, including therapies, mobility aids, dental care, and more.

One of the more promising results achieved within the pilot was demonstrating the ability to link Gillette patient data with

external claims data. CPCC used these data to understand the impact that care coordination has on patients' utilization of medical services, such as emergency department visits and hospitalizations. The early findings illustrated above reveal fewer emergency department visits and hospitalizations for a small number of patients enrolled in care coordination.

Goals for the Future of Care Coordination at Gillette

The CPCC program team aims to have enrolled 375 patients by July 1, 2024. More broadly, the team hopes to implement collaboration between Gillette's Infant and Toddler Development evaluation and Pediatric to Adult Healthcare Transition teams at Gillette. By offering end-to-end clinical service in this way, patients are getting the collaborative, proactive care they deserve.



To learn more about care coordination at Gillette email providerrelations@gillettechildrens.com.

Identifying Motor Delays in Children and When to Refer Patients

Gillette Motor Delay Clinic physicians **Nicole Williams-Doonan** and **Marcie Ward** are keen to offer their expertise, especially when it means earlier treatment for children who have motor delay or regression.

Identifying motor development issues early on is highly beneficial to a child's health and well-being, as early treatment can make a big difference to the child's further development and quality of life. Early intervention means earlier education, observation, therapy, and partnership with a medical team, all of which benefits the child.

"No discussion or evaluation is too early, and parents should be encouraged to report any concerns about their child's development, such as an abnormal gait, hypotonia, or a parent's persistent sense that something just isn't right," says Dr. Ward. "A primary care provider can determine if the issue is a variation of typical development, if it warrants a referral to a specialty care provider like Gillette is the best approach."

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 with more complex movements. In atypical development, this is not always the case. Additionally, if a child regresses in motor development, they should be urgently referred to a neurologist.

Whatever the cause of motor delay, information and answers always help. Families can get peace of mind from Gillette experts with an Infant and Toddler Development or Motor Delay Evaluation.





Nicole Williams-Doonan



Marcie Ward

When should you take action?

 Typical	 Red Flag
When pulled to sit, the child's head comes up without difficulty or delay.	Significant head lag at five months
Can sit without using hands to prop themselves up and can maintain sitting while reaching for something	Not sitting independently by 7 months or unable to get into sitting position by 9 months
Toddler can rise from supine position on the floor and is walking well by 12-16 months	Unable to rise from floor and stand unassisted by 18 months.

If any of these red flags appear, a primary care provider should refer the patient to a specialist, such as a pediatric neurologist or genetic counselor. The earlier the disease and any comorbidities are identified, the earlier helpful medications and therapies can begin.



For more information on early identification of delays at Gillette, visit gillettechildrens.org.

To refer a patient online, visit gillettechildrens.org/refer.

A Strong Start for Ernesto

Gillette Infant and Toddler Evaluation offers early treatment for developmental delay

I simply wanted the best for my child, so we went to Gillette Children's for an Infant and Toddler Development Evaluation," says Dalia Prieto.

Her son, Ernesto, was born prematurely at 24 weeks, and spent the early days of his life in a neonatal intensive care unit in a Minneapolis hospital.

Shortly after he was born, Ernesto was diagnosed with cerebral palsy (CP). Gillette Children's Cerebral Palsy Institute is the world's foremost innovator in clinical care, research, and patient advocacy. It brings together more than 140 specialists and insights from 100 years of historical and current studies on CP.

Helping children with CP thrive

Ernesto's primary pediatrician knew he would need the services of a strong medical team and requested an Infant and Toddler Development Evaluation appointment at Gillette.

Gillette has the largest group of infant and toddler evaluation and treatment experts in the Midwest. The team includes a physiatrist (often called a physical medicine and rehabilitation [PM&R] physician), neurologists, and trained therapists. These experts analyze the results of multiple assessments and work with families to create a comprehensive treatment plan.

Care and treatment for Ernesto

"The team at Gillette answered my questions and outlined the services Ernesto would need," Dalia says. "It was a relief."

Ernesto is now 2 years old and meets regularly with an occupational therapist, physical therapist, speech therapist, neurologist, and his care is overseen by Mark Gormley, Jr., MD, PM&R physician.

"I love coming to Gillette," Dalia says. "I enjoy the therapists and they do a great job of telling me what they're working on with Ernesto and how I can help him at home."

Expert, compassionate therapists make a difference

Ernesto's occupational therapist, Kathleen Maroney, has been working with him for over a year.

"As an occupational therapist, I am trained to look at the whole child," Maroney says. "I assess each child to see where they are functioning in the expected developmental areas

of fine motor and adaptive behaviors, such as regulation and sensory processing. I also look at self-care skills such as feeding, dressing, grooming, and physical processing," Maroney adds.

"Ernesto is a delight! He works hard and is very social," Maroney says.

His physical therapist, Katherine Kaiser, agrees and aims to make his therapy sessions fun and productive.

She gives Ernesto bells to ring and entices him to walk farther by blowing bubbles and placing toys around the gym.

Maroney, Kaiser, and the entire Gillette Infant and Toddler Development team are ready to support parents and help children live their best lives.

"I enjoy the therapists and they do a great job of telling me what they're working on with Ernesto and how I can help him at home."

—Dalia Prieto



To learn more about how the Gillette Infant and Toddler Evaluation team can help your patient, call 651-325-2200.

SPRING 2024

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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
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Pediatric to Adult Health Care Transition Summit

Thursday, June 13, 2024

Register to attend in person
or virtually before May 30

Location:

Holiday Inn & Suites St. Cloud,
an IHG Hotel
75 37th Avenue
St. Cloud, MN 56301

Overview:

The Pediatric to Adult Health Care Transition Summit will offer participants valuable insights into enhancing programs and overall state practices regarding pediatric to adult healthcare transition (HCT). This progress is urgently needed to support the growing number of youth with special health needs aging into adulthood.

This summit is hosted by Gillette Children's in collaboration with the COPIC Medical Foundation, Got Transition, and the Minnesota Department of Health.

Transition Summit Topics:

- Incorporating Youth and Family Experience to Ensure Patient and Family-Centered HCT
- Applying Principles of Equity and Trauma-Informed Care into Practice
- Lunch + Learn: Happenings at the State and National Level
- Innovation and Systemwide Incorporation of HCT Initiatives Across Minnesota and the Country
- Breakout Discussions: Moving the Dial on HCT in Your Setting



Continuing Medical Education (CME) Credit:

Gillette Children's is accredited by the Minnesota Medical Association (MMA) to provide CME for physicians and takes responsibility for the content, quality, and integrity of this educational activity.

Gillette Children's designates this live activity for a maximum of 6.5 AMA PRA Category 1 Credits™. Physicians should claim only the credit commensurate with the extent of their participation in the activity.



Register
now!