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On the cover: Kate Ketelhohn meets with her orthopedic surgeon Mark Dahl, MD, to discuss her limb lengthening procedure outcomes.

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About Our Journal

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Micah Niermann, MD Chief Medical Officer & **Executive Vice President** of Clinical Affairs

Dear Colleagues,

At Gillette Children's, we provide comprehensive care planning that considers the whole child, especially those living with complex medical conditions.

Our Complex Care team centralizes care coordination for children and adolescents with chronic and complex medical conditions. We look at your patient from head to toe and proactively partner with you, the family, and the patient's other specialty providers, regardless of the health system, to support each patient's unique care needs.

You can learn more about how our collaboration and coordination efforts impacted one particular family on page 11.

If you have a patient with rare or complex medical conditions, I highly recommend you look to the Complex Care team at Gillette as a partner to address their care needs.

Thank you for helping every child create their own story.



CARF Reaccredits Rehabilitation Program for Maximum 3 Years

 illette Children's has received the Commission 🕒 on Accreditation of Rehabilitation Facilities (CARF) reaccreditation based on this year's survey. The three-year accreditation will extend through November 2025.

Gillette is among a small number of U.S. inpatient rehabilitation facilities with this highly sought-after credential for both pediatric specialty and brain injury specialty programs. This reaccreditation is a recognition of relentless commitment to improving the quality of life for patients and communities, as well as a continuous pursuit to improve the patient experience.



One CARF surveyor notes, "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."

Gillette boasts a comprehensive, integrated inpatient rehabilitation program that is a vital part of the continuum of care and provides access to the highest concentration of pediatric rehabilitation medicine specialists in the nation.

Gillette is among a small number of U.S. inpatient rehabilitation facilities with this highly sought-after credential for both pediatric specialty and brain injury specialty programs.

Gillette Joins Pledge to Decarbonize Health Care Sector

Gillette was celebrated by the U.S. Department of Health and Human Services (HHS) at the 2022 United Nations Climate Change Conference (COP27)



United Nations Climate Change Global Climate Action

for pledging ongoing action to decarbonize the health care sector and make health care facilities more resilient to the effects of climate change. Gillette has formally committed to pursuing the Biden administration's climate goal of reducing emissions by 50% by 2030 and achieving net zero emissions by 2050.



Gillette Children's Awarded \$1.5 Million for Research Investigative Lab

Gillette has always focused on research to improve patient care from the time of diagnosis to intervention and recovery. A new research lab will help bring teams together to conduct research related to the assessment of motor control, movement disorders, spasticity, and pain. The lab will include a rehabilitation research and clinical care space needed to advance the development of biofeedback, robotics, and exoskeleton development.

"Research is a crucial driver of how we advance diagnosis and treatment interventions for pediatric musculoskeletal and neurological conditions," said Gillette Children's President and CEO Barbara Joers. "This project will fund critical infrastructure to expand Gillette Children's research capacity and capabilities, positively impacting the lives of many children and their families."



Craniofacial and Plastic Surgery Available in Duluth, Minnesota

G illette Children's is excited to announce pediatric craniofacial and plastic surgery services in Duluth, Minnesota.

On the fourth Monday of every month, our pediatric craniofacial and plastic surgeons, Jo Barta, MD, and Courtney Carpenter, MD, will have appointments in our Duluth Clinic to offer families in northeastern Minnesota convenient access to specialty services.

Gillette is home to one of the largest and best craniofacial programs in the U.S. The team at Gillette includes craniofacial and plastic surgeons, neurosurgeons, dentists, orthodontists, speechlanguage pathologists, advanced practice pediatric nurse practitioners, audiologists, dieticians, and feeding specialists. The American Cleft Palate Association has certified Gillette as a site for cleft care.

Gillette's craniofacial and plastic surgery care includes:

Torticollis

Hemangioma

Polydactyly

- Cleft lip and palate care
- Craniosynostosis
- Ear molding
- Plagiocephaly

Gillette also offers virtual consultations for pediatric craniofacial and plastic surgery services. The craniofacial

team at Gillette Children's is your partner at every stage of diagnosis and treatment.



Learn more about craniofacial and plastic surgery services at Gillette.

Direct Gillette Appointments for Common Concerns

Quick Care Clinic

Your established Gillette patient can get their minor medical needs met at the Gillette Quick Care Clinic on a same-day or next-day appointment basis.

Gillette families can call **651-229-3890** and ask for a Quick Care appointment.

The Quick Care Clinic can help your patients with minor illnesses that might be more complex due to a chronic medical condition like:

- Bowel difficulties like constipation
 or diarrhea
- Feeding intolerance like nausea or vomiting
- G-tube concerns
- Urinary difficulties
- Fever
- Respiratory symptoms

Infant and Toddler Development Evaluation

When it comes to child development, time is of the essence. For your patients aged 0–24 months old experiencing developmental concerns, the Gillette Infant and Toddler Development Evaluation is actively seeing patients within two weeks of an appointment request.

Although any child may experience developmental delay, our neurodevelopmental experts keep a close eye on risk factors like:

- Children born before 33 weeks
- Needing extended oxygen support in a neonatal intensive care unit or upon discharge
- Abnormal head ultrasound
- Illness at or around the time of birth
- Hypoxic Ischemic Encephalopathy, with or without cooling protocol
- Infant developmental concerns
- Persistent fisting hands
- Persistent head lag
- Delayed sitting
- Stiffness or tightness in legs
- Hand preferences before 12 months
- Asymmetry in postures or movements



Make a referral or learn more about Infant and Toddler Development Evaluations at Gillette.



A Closer Look at FEES Testing

A Fiberoptic Endoscopic Evaluation of Swallowing (FEES) test uses a small, flexible tube called an endoscope which allows a fiber optic camera with a small light to be inserted into a child's nose. Images from this camera are shown on a screen so providers can see parts of the throat, nasal passages, and how the muscles work during swallowing.

Gillette craniofacial speech-language pathologist, Graham Schenck, PhD, is specially trained in the procedure. He often teams up with Gillette pediatric otolaryngologist, Micah Berman, MD, to conduct the 20-minute FEES test.

A FEES test can help identify children who might be suffering from dysphagia which, in some cases, might make a child feel as if they are having trouble swallowing or like something is stuck in their throat.

Amelia Mickman Weicker recently took her newborn son, Gryffin, to Gillette for a FEES test and had this to say: "Gryffin was having some feeding issues, and I felt Dr. Berman and Dr. Schenck took the time to talk to me and answer any questions I had. Gryffin was a champ and really had little to no discomfort during the test."

Progressing from Research to Practice

Knowledge translation bridges the gap for the Cerebral Palsy Institute

Gillette Children's Cerebral Palsy Institute is dedicated to promoting independence and improving the quality of life for individuals with cerebral palsy (CP). Led by a team of renowned experts in the field, the Cerebral Palsy Institute helps shape the future of CP care and research.

Gillette chose Andrea Bushaw, PhD, APRN, CPNP, manager of clinical transformation, and Tom Novacheck, MD, pediatric orthopedic surgeon, to lead the Institute's knowledge translation efforts.

Knowledge translation refers to the process of moving research findings into practical applications that can improve people's lives. In the case of the Cerebral Palsy Institute, the knowledge translation team aims to implement discoveries and advancements in the care of cerebral



Tom Novacheck, MD



Andrea Bushaw, PhD

palsy, informing clinical practice, program development, and public health policy.

"Simply put, we work to narrow the research-to-practice gap by creating evidence-based system changes that are scalable, sustainable, and measurable," says Dr. Bushaw. "To accomplish that aim, our approach is to increase collaboration among researchers and clinicians, reduce the time for research evidence to reach clinical practice, and share our expertise with others in the field."

Current Accomplishments

One of the highlights of the knowledge translation program at the Institute is the staffed Clinical Transformation Specialist role, which is a clinically credentialed evidence-based practice (EBP) mentor and implementation science expert. EBP is a problem-solving approach that integrates patient values, clinician expertise, and the best available evidence to inform decisions for a specific patient.

In addition to adding staffed clinical transformation roles, the group launched a clinical practice pilot for hip surveillance in patients with cerebral palsy. "We've implemented the American Academy for Cerebral Palsy and Developmental Medicine's (AACPDM) hip surveillance care pathway, starting with a cohort of patients who have CP and multidisciplinary needs," says Dr. Novacheck. "We anticipate fully implementing the pathway by the end of 2023. Other aspects of proactive, multidisciplinary care were also included as part of the pilot."

By bridging the gap between research and practice, knowledge translation can transform health care and improve health outcomes for individuals who have CP.



Knowledge Translation Education Conference a Rousing Success

In February, the Cerebral Palsy Institute's Knowledge Translation group hosted a full-day conference promoting the translation of recent CP research into Gillette clinical practice. Two areas were highlighted: 1) The muscle pathology of CP and 2) The effects of hypertonia and its treatment on muscle function and gross motor function.

If you are interested in learning more about the topics covered at the first Knowledge Translation Education Conference, please email Andrea Bushaw at andreabbushaw@gillettechildrens.com.

Looking Ahead

The future of knowledge translation at the Cerebral Palsy Institute looks bright. Dr. Bushaw says, "By 2030, I hope to have a fully operationalized learning health system where we can systematically gather and create evidence, as well as apply the most promising evidence to improve the care of our patients."

"I am most excited to fully implement Mosaic, which has multiple aims. It will allow

us to manage an individual's care from the database, perform internal outcomes research, and contribute data to the Cerebral Palsy Research Network (CPRN). A crucial element of this work includes collecting and storing data in new ways, so researchers and clinicians can ask population-level questions about our CP patients and evaluate individual patient data longitudinally," says Dr. Novacheck.

Motorized Plate Lengthening

A viable option for congenital limb differences

The latest limb lengthening study out of Gillette Children's reports an innovative technology for the limb lengthening of femurs in small children. In the paper "Motorized Plate Lengthening of the Femur in Children: A Preliminary Report," published in the Journal of Pediatric Orthopaedics, pediatric orthopedic surgeons Mark Dahl, MD, and Andrew Georgiadis, MD, prospectively collected data on a new limb lengthening implant starting in the fall of 2020 and into the early part of 2021.

Seven patients ages 2–9 received femoral lengthening surgery with a magnetic lengthening plate. "Because the implant is new, our goal was to be very rigorous in our documentation of outcomes, including details of their lengthening, radiographic outcomes, and complications to present the public with a good idea of its true utility," says Dr. Dahl.

This research touches on a difficult aspect of limb lengthening treatment in young children with smaller bones. Small bones present a challenge because they still have open growth plates and anatomically may not be able to support an implant that goes inside the bone until a child's pre-adolescent or adolescent years. Currently, most literature represents external fixation as the best choice for lengthening small bones. Dr. Dahl at Gillette Children's has worked towards an alternative treatment paradigm for years.

Pediatric orthopaedic surgeon Mark Dahl, MD, has worked toward an alternative treatment paradigm for limb lengthening for years.



A. She underwent magnetic plate lengthening with acute deformity correction through the lengthening site, and guided growth to her knee.

"We were the first to publish about using an 'inside of the bone nail' outside of the bone, which is an off-label use that has been successful," Dr. Georgiadis says. "We employ that method sometimes, but it's not as good as an implant specifically designed to be outside the bone." The current study evaluates just such an implant, one that goes inside the body but outside of the bone, intending to be safer for smaller bones in younger kids.

Successes and Difficulties of Treatment

In the new study, the team had two main conclusions. First, they found this kind of technology where a plate can distract and lengthen a small bone appears to be viable. Secondly, all seven young children had successful lengthening of the A 9-year-old girl with fibular hemimelia and congenital short femur had a previous history of hip surgery and right femoral lengthening. Preoperatively, her discrepancy was 10 cm.



B. After a 4.4 cm lengthening (14% of femoral length), she had a 5.3 cm discrepancy.

femur and experienced the same rate of complications and difficulties as other ways of lengthening, including external fixators. There are some complications unique to congenital limb quality compared to a child born with the normal limb who then developed a limb lengthening quality because of injury or infection. Dr. Dahl explains, "If you have a congenital limb lengthening quality, we can take away some of those burdens with better implants, but the implants don't change the underlying diagnosis or some of the underlying difficulties that come with surgical lengthening."

"The study itself is, I think, scrupulously open about the successes and difficulties



C. Notice neutral alignment at the terminus of the lengthening.

in treating these patients," Dr. Georgiadis says. Future research in this subspecialty is forthcoming. "We have a number of active projects in surgical lengthening of both acquired and congenital limb discrepancies, including some technical ways to do both corrective osteotomy and limb lengthening at the same site, which is very sparsely reported on," Dr. Georgiadis says. "We're excited to add to that body of work."

Gillette Children's is a referral center for complex limb differences. Led by Dr. Dahl, who has been performing limb length surgeries for more than 35 years, the limb lengthening and reconstruction team at Gillette is recognized both nationally and internationally.



Two Lengthening Technologies

Doctors have been performing limb lengthening for more than 100 years, but the techniques have changed significantly even in the last 15 years. One of the most common new treatment options is limb lengthening with implants that go inside the body and are lengthened using a handheld device.

Limb Lengthening via Implant

The lengthening implant is placed, and one or two weeks post-surgery, the patient's family initiates the lengthening process themselves at home. An external device with a magnet inside is placed on the limb. The family uses the device to telescope and lengthen the leg slowly over weeks, often 6 to 8 times per day, with each lengthening episode lasting about 20 seconds.

"The lengthening process is unique in that a surgery happens, but the treatment is really done by the family at home," Dr. Georgiadis explains. "From there, the family checks in with us on a weekly basis so we can clinically assess the lengthening site radiographically and adjust the lengthening rate and rhythm as needed. We routinely check in with patients who live out of state during a virtual visit using digital radiographs."

Though implants for limb lengthening have come a long way, for young children with smaller bones, external fixation is still a common treatment avenue.

Limb Lengthening via External Fixator

An external fixator is an apparatus with carbon fiber rings, stainless steel pins, and wires that traverse the skin. Using this device to lengthen a femur, results in a significant amount of pin care, including cleaning all the sites where pins and wires enter the child's leg. As the leg is lengthened, those pins and wires can cause discomfort and scarring. While external fixators are necessary for specific situations, there is a move away from these devices for most limblengthening surgeries.

"External fixators have unique complications both physically and psychologically for a child and family," Dr. Georgiadis says. "We want to decrease the burden on the family undergoing limb lengthening as much as possible, so we try to use these internal methods whenever we can." RESEARCH

Gait and Motion Analysis
 Rehabilitation Therapies

Examining Social Determinants on Patient Care

Study bolsters Gillette's commitment to better understanding unique patient population needs

While completing work on his doctorate at the University of Minnesota, Matthew Witham, PhD, LMFT, director of child and family services at Gillette Children's, developed an interest in the connection between clinical mental health outcomes and a patient's social and environmental circumstances. After discussing this with Rhonda Cady, PhD, RN, clinical scientist and health services research program lead, they grew curious about how these factors might overlap for children with complex medical conditions at Gillette.

Since Gillette doesn't collect patient data related to social factors such as homelessness, free and reduced lunch, and Child Protective Services (CPS) involvement, Cady and Witham reached out to the University of Minnesota's Center for Advanced Studies in Child Welfare (CASCW) to dig deeper. This partnership kicked off a formal study "This partnership has helped us better understand the many social factors that influence our patients' lives. This information is often not shared during patient appointments, and now we have a better understanding of their diverse needs." —Matthew Witham, PhD. LMFT and allowed them access to a CASCW database (Minn-LInK) that aggregates statewide data collected by the Minnesota Department of Human Services and Minnesota Department of Education. "This partnership has helped us better understand the many social factors that influence our patients' lives," Witham said. "This information is often not shared during patient appointments, and now we have a better understanding of their diverse needs."

When comparing Gillette-specific data against information available through Minn-LInK, Cady and Witham found an overlap with 34,000 unique patients who received care at Gillette between 2016–2018. With this information, Gillette can use this data to better understand our patients and what they face outside the hospital's walls. For example, an in-depth analysis showed higher occurrences of MFIP and SNAP use, involvement in

New Clinical Scientist Rounds Out Research Team at Gillette

Gillette Children's research mirrors its clinical care: it is collaborative and multi-disciplinary. It is focused on childhoodonset medical conditions and rare diseases. Gillette has teams of experts from multiple fields who work together to better understand these conditions, evaluate current and potential treatments, and improve outcomes. Many institutions focus on common conditions for their clinical care and research. Gillette focuses on complexity and conditions that are relatively uncommon.

With the addition of Alyssa Spomer, PhD, the Gillette research team now has a dedicated clinical scientist for each of its seven distinct programs. Dr. Spomer joins Gillette from the University of Washington, where she recently earned her PhD in Mechanical Engineering after defending her dissertation, "Evaluating adaptation to multimodal biofeedback in cerebral palsy."

Dr. Spomer says, "As a researcher, I came to Gillette Children's not only because of its international reputation in pediatric medicine, but because it provides the opportunity to work with leading experts across multiple disciplines to directly impact patient care. The priority that Gillette places on teambased, innovative care means I can perform research that is intentionally crafted and clinically meaningful."



Director of Research at Gillette, Joyce Trost, PhD, PT, says, "Having a clinical scientist dedicated to each of our research programs is a huge step forward for Gillette research and an amazing accomplishment for an organization of our size. I'm excited to see what the future holds for patients as we continue to focus on our mission-driven research."



To learn more about research endeavors at Gillette, visit gillettechildrens.org/research.

special education services, and higher incidences of out-of-home placements in children with cerebral palsy, spina bifida, epilepsy, and neuromuscular disorders, as compared to the general Gillette patient population.

Through continued research, Cady and Witham are committed to better understanding the social complexities of Gillette's unique population, how they contribute to outcomes in care, and how this insight might help patients around the world. "Whatever we uncover through this study will be used to inform health care and family care," says Cady. "This is incredibly important for an institution like Gillette that is so involved in medical complexity and care delivery."



Want to partner on a research study? Get in touch with our research team at 651-325-2200.

Our Clinical Scientists

Gait and Motion Analysis

Under the direction of Joyce Trost, PhD, PT, and Jennifer Laine, MD, the Gillette research department leads interventional and observational research studies across seven distinct programs.

Liz Boyer, PhD Andy Reis, PhD

Orthopedics

Susan Novotny, PhD





Physical Medicine & Rehabilitation



Alyssa Spomer, PhD

Health Services



Rhonda Cady, PhD

Pain and Comfort



Chantel Burkitt, PhD

Neuroscience



Mo Chen, PhD

Spine



Sara Morgan, PhD

Genetic Testing and Your Patient Families

Families deserve an expert, empathic genetic counseling experience

by Tim Feyma, MD, Pediatric Neurologist

When genetic testing is needed for a complex medical condition, working with a team that can help proactively counsel the family on what to expect is vital. Parents frequently report that genetic testing is a stressful, anxious experience, even when results are conclusive.



As genetics continues to discover new conditions, detailed testing often finds genetic changes that we as providers may not fully understand, let alone a patient family. Variants of Unknown Significance, or VUS, are frequent findings in genetic testing and have many potential causes.

- First, because genetic conditions may be inherited, a VUS could guide us to further test a child's parents to better explore if a genetic change is the answer.
- A VUS could be related to mutations that happen in a developing fetus that have nothing to do with a parent's genetics.
- Finally, we could find that the VUS is relatively normal. Because our genetics are all different, some degree of uniqueness is present in the genetic material of everyone, so a VUS may not be significant.

These options scratch the surface of further questions a family might have after an initial inconclusive genetic test. At Gillette Children's, genetic counselors, geneticists, and neurologists assist with all aspects of genetic testing and discovery with a patient family.

A Diagnostic Quest

The neurology team at Gillette is happy to partner with families in what might become a diagnostic quest to find answers for their child.

As part of that journey, we discuss with the family what genetic testing means, interpret the genetic reports, provide counsel regarding results, and guide further family testing. Beyond the interpretation of results from a genetic test, there is no single genetic test, and sometimes choosing the best test and subsequent tests will require the assistance of a skilled team.

Our team also supports educational needs and the complicated path of insurance authorizations. Families deserve this holistic view of their genetic testing experience, and my team and I are proud to provide it for them.



Cerebral Palsy and Genetics: What's the Connection?

I am often asked about the link between cerebral palsy (CP) and genetics. CP is a term that has long been used to refer to a condition affecting body movement after injury to the brain in the fetal or infant child. From there, CP is further classified by the extent to which it involves body movements (hemiplegia – half the body affected, quadriplegia – all four limbs affected, etc.) and the type of movements of that body, like spastic (tight muscles with overactive reflexes), dystonic (twisting limb movement with normal reflexes), and other forms of movements that are tough to limit to one description.

Despite all these identifiers, there has always been some confusion about the accurate diagnosis of CP. For example, with the assistance of modern diagnostic tools like magnetic resonance imaging (MRI) or computed tomography (CT) scans of the brain, we find that some patients have a CP "mimic," that is, they seem to have the movements associated with CP, but do not have an identifiable brain injury.

Fortunately, genetics has begun to fill in our understanding of many of these more confusing circumstances. As science continues to discover more about human genetics and medical conditions, many cases thought to involve a CP mimic are more often found to have genetic causes for their condition.

Bringing Ease to Complex Pediatric Care

Gillette's Complex Care team works to make the lives of patients and their families less complicated

A melia Mickman Weicker of Minneapolis had some mild concerns immediately after the birth of her son, Gryffin, in August 2022. "Gryffin was having some difficulty feeding right after he was born," Mickman Weicker recalls. "The doctors noticed he had different physical features and ordered some genetic testing. They took a blood sample and sent it to a lab in Iowa. My husband and I waited for six weeks to get the results."

The first few months of Gryffin's life were a blur for Mickman Weicker.

Gryffin was diagnosed with 9Q34 Duplication Syndrome. It is a rare genetic disorder that can cause intellectual and developmental delays. "In the beginning, I saw providers in eight different health care systems, and there was not much coordination," she says.

She shared her frustrations during a lactation consultation appointment, and that provider suggested she investigate Gillette Children's and its pediatric complex care team.

"Now, Gillette assists me with coordinating his care, and it has made a big difference for my family." —Amelia Mickman Weicker, Gryffin's mother

Making Complex Care Easy

In his first month of care at Gillette, Gryffin has seen specialists in feeding, craniofacial, orthopedics, neurology, speech-language pathology, and rare disease. Often, these appointments occurred on the same day to cut down on travel and scheduling inconveniences. Mickman Weicker says, "The team at Gillette is really on top of things, and I'm grateful I don't have to run all over town to see various specialists."

Gryffin has been fitted for a special harness to help with hip dysplasia and a CranioCap orthosis to help improve his head shape. He's also visited the Gillette Aerodigestive Clinic, where he completed a Fiberoptic Evaluation of Swallowing (FEES) test to provide a better understanding of the anatomy of his throat. The Complex Care team at Gillette has helped Gryffin Mickman Weicker's family manage the treatment for his rare genetic disorder.

Partners with Parents and Providers

"Gillette is really starting to feel like a second home to me," Mickman Weicker says. "The providers here take the time to answer my questions. They help me schedule his appointments and suggest other specialists we should see."

The Gillette Complex Care team wants referring providers and parents to know about the comprehensive and convenient way our specialists work together to be a valuable partner in caring for children with complex medical needs.

Mickman Weicker wants parents of children with complex medical needs to know there's support, and they are not alone.

"At first, I felt like I was the only person that had all the pieces to coordinate Gryffin's care," she says. "Now, Gillette assists me with coordinating his care, and it has made a big difference for my family." SPRING 2023

Gillette Partners in Care JOURNAL

Partners in Care Journal is a publication of Gillette Children's.

The team at Gillette Children's knows that expertise regarding complex conditions is almost as rare as the conditions themselves. We strive to share our knowledge with providers across the world to positively impact patient care for generations to come. That's why we partner with you at every stage of your referral journey.

We respond daily to comments and questions submitted via email at providerrelations@gillettechildrens.com

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-004

Gillette Partners in Care

Conference

Save the Date!

Partners In Care Conference — Virtual for primary care physicians and providers

Friday, October 6, 2023

7 a.m. to Noon

Topics include:

- Spine
- Non-surgical orthopedics
- Club foot
- Urology & Spina bifida
- Endocrinology
- Neurosurgery
- Infant development evaluations
- G-Tube management

Registration opens May 1, 2023



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