

## Clinic Spotlight:



### **Gillette Children's Specialty Healthcare**

200 University Ave. E.

St. Paul, MN 55101

1-800-719-4040 (toll-free)

[www.gillettechildrens.org](http://www.gillettechildrens.org)

### **Core Team**

Arthur Beisang, M.D., pediatrician

Tim Feyma, M.D., pediatric neurologist

Raymond Tervo, M.D., neurodevelopmental pediatrician

Robert Wagner, M.D., family medicine physician and Director of Adult Services at Gillette Lifetime Specialty Healthcare

Jason Kelecic, D.P.T.

Rett Syndrome Program Manager

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Program Resource Nurse-Rett Syndrome

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### **1. What is Gillette's philosophy regarding caring for children who have Rett syndrome?**

At Gillette Children's Specialty Healthcare, we believe in focusing on the specific needs of each girl and each family. There are no textbook cases—each girl is her own textbook. We work closely with families to develop a care plan that's appropriate for their child, based on our experience and the latest information and research about Rett syndrome. We also believe that our care shouldn't end when a child reaches adulthood, so we've developed specific clinics for adults with childhood-onset disorders, like Rett syndrome.

Until there's a cure or definitive treatment for Rett syndrome, we will continue working to minimize the condition's effects. Treatment at Gillette often includes seizure management and other medical therapies, such as orthopedic and pulmonary care. We also incorporate rehabilitation therapies and assistive technology to slow the loss of abilities, improve or preserve movement, encourage communication, and increase social contact.

Gillette is committed to family-focused care. That means you and your daughter are key members of the care team—your goals and needs help drive the care we provide.

## **2. What is the scope of Gillette's Rett Syndrome Program?**

We specialize in treating children, adolescents and adults who have disabling medical conditions that begin during childhood, including Rett syndrome. We focus on providing specialty care to maximize both ability and quality of life. For example, we have the largest group of pediatric orthopedic surgeons in the region. Because of this expertise, Gillette is able to identify how a girl's bones and muscles are affected by Rett syndrome and to work within a team of specialists to provide optimal care. When spine surgery is needed, our specialists work with our entire team and the family to plan and perform this delicate procedure. Our specialists perform hundreds of spinal surgeries each year for children and adults with special needs.

We recognize that coordinating care for one child among several specialists can be a challenge for any family. That's why the Rett Syndrome Program at Gillette is headed by pediatricians and family practice providers who specialize in children and adults with special needs. From diagnosis to management throughout a lifetime, our core team is able to help patients and families identify their current needs, anticipate future ones and avoid getting lost in the health care system.

## **3. Tell us more about the history of Gillette's Rett Syndrome Program.**

About eight years ago, a group of parents from the Minnesota Rett Syndrome Research Association (MRSRA) approached us about developing a specific Rett Syndrome Program. The idea seemed like a logical fit, as Gillette already provided much of the specialty care that the girls in the region were receiving. Combining resources and coordinating care, as well as acting as a liaison with other local primary care providers and community groups, became our focus. Our partnership with the MRSRA increased awareness of not only what was possible, but also what was necessary to improve the girls' lives. Gillette's Rett Syndrome Program became part of our Center for Pediatric Neurosciences, and we currently care for more than 90 girls and young women. As the girls' needs became more evident, we developed staff competency and expertise in several areas, including:

- Specialized pediatricians, neurologists, rehabilitation medicine specialists, orthopedic surgeons, pulmonologists, gastroenterologists, and cardiologists who care for people who have Rett syndrome as a regular part of their practice
- Physical and occupational therapists who are accustomed to caring for children and adults who have Rett syndrome and experienced with both acute and chronic concerns
- Speech and language pathologists who are experienced with augmentative and assistive communication devices, from the simplest pick board to a sophisticated eye gaze device.
- Assistive technology specialists who design and customize braces, seating systems and mobility devices to help patients be as independent as possible.

#### **4. What should a patient expect from a first-time visit to Gillette?**

We serve patients throughout a five-state region and beyond, so excellent care coordination is essential, and it begins well before the first appointment. Our core team works closely with the family and the many primary providers and specialists who might already be involved in a girl's care. We consult by phone with each girl's family and sometimes with her primary care providers before the first clinic visit, to anticipate her medical needs and maximize the benefits of an appointment at Gillette. We try to provide access to vital services and evaluations while avoiding unnecessary ones. Our resource nurse thoroughly reviews a girl's history and needs prior to a visit, arranges all the details with families before they arrive, and serves as a resource for coordinating care after the family arrives. In many instances, a girl can be seen by several physicians and clinicians in a single visit. When a new girl with Rett syndrome is identified, we can connect her and her family with other families, to provide additional support and create a network for her benefit.

#### **5. Can you describe the role of research at Gillette?**

At Gillette, our Rett Syndrome Program emphasizes addressing the symptoms each girl experiences and reducing their impact in daily life. Similarly, our research is focused on clinical care—how we can take better care of a patient who has Rett syndrome. We collaborate with researchers at the University of Minnesota to extend our care beyond the clinic, so we can better understand how girls with Rett syndrome interact with their family, home and school environments.

Our current research initiatives are focused on how girls with Rett syndrome both interpret and communicate about pain, including inspection of specific biomarkers and triggers of behavior. As new biological and chemical therapies are developed, Gillette hopes to be a leader in understanding their effects and benefits in both the clinical and community setting. Our staff at Gillette and our colleagues at the University of Minnesota look forward to future collaboration with other university medical centers that wish to research treatment and care of children who have Rett syndrome.

**Program initiation:** Autumn 2005

**Number of Patients Followed in 2011:** 96

**To Schedule an Appointment:** Follow the contact information above, or call 1-800-719-4040.

**Eligibility, Referral Process and Insurance:** Gillette accepts referrals from other medical providers, as well as self-referrals. Our staff will work with you to determine your specific needs. No family will be turned away.