

# Rett Syndrome Education Day



**Time**  
Saturday, April 29, 2023  
8am to 4:30pm

**Location**  
River Park Plaza, Ground Floor,  
10 River Park Plaza, St. Paul, MN

**Registration is required  
for this free event**  
[gillette.mn/rett](http://gillette.mn/rett)



**Registration  
Deadline**  
Friday, April 14

## Welcome Back to our Annual Education Day!

After a two-year break, WE ARE BACK and ready to share some exciting updates on drug trials and gene therapy!

- The Midwest Rett Syndrome Foundation (MRSF) welcomes families and caregivers for a day of learning and networking. We have real treatments coming to help our children!
- This full day of adult conversation will focus on research updates and local opportunities to get the most out of our Center of Excellence at Gillette Children's.
- There will be information tables, giveaways and special introductions throughout the day!

For questions, contact **Lisa Evert 507-330-3315** or [lisaever68@gmail.com](mailto:lisaever68@gmail.com)

## Schedule

8-8:45am	Check-In and Continental Breakfast
8:45-9am	Welcome and Introductions
9am-Noon	<b>Research Updates and a New Therapy Program Launch</b> Exciting advancements have been announced related to treating Rett syndrome. This panel is ready to update you and take your questions! We will also announce the new therapy program at Gillette focused on neuro-habilitation with Rett syndrome. Panelists are listed below. A break will be offered during this session.
Noon-1:15pm	<b>Free Lunch Onsite and Networking (Day Camp will be closed during this time.)</b>
1:15-2:15pm	<b>Assessing and Understanding Pain in Non-Verbal Patients</b> Chantel Burkitt, PhD; Frank Symons, PhD Diagnosing pain in non-verbal patients can be frustrating and challenging. We will share tools and tips on how to measure and track your child's pain. Learn how your pain management approach can be helpful when utilizing the multi-disciplinary care available through the Rett clinic.
2:15pm	Break
2:30-3:30pm	<b>Parents Helping Parents</b> Traveling, adaptive recreation, gadgets on Amazon and so much more! Join this group of parents as they share their experiences, tips and advice on navigating life's challenges. Participants should come prepared to take notes and share their own tips too! Moderator: Matt Dahms, parent to Bennett, age 13
3:30-4:30pm	Social/Cocktail Hour Upstairs

## Panelists/Presenters

Art Beisang, MD, Complex Care Pediatrician, Gillette Children's  
Chantel Burkitt, PhD, Clinical Scientist, Gillette Children's  
Breanne Byiers, PhD, Research Associate, University of Minnesota  
Tim Feyma, MD, Pediatric Neurologist, Gillette Children's  
Dominique Pichard, MD, Chief Science Officer,  
International Rett Syndrome Foundation  
Frank Symons, PhD, Associate Dean for Research and Policy,  
University of Minnesota

## Hotel/Accommodations

- DoubleTree by Hilton, 411 Minnesota Street, St. Paul, MN  
Discounted rate for Friday, April 28 at \$169+tax.  
Additional nights at the standard rate. Use code 911.  
Parking \$22/day+tax. Reservations must be made by April 2.
- Call 651-291-8800 or book online at [gillette.mn/Hilton](http://gillette.mn/Hilton).

## Day Camp Experience

Given that Rett Ed Day is designed for an adult audience, we are offering a day camp experience for school-aged siblings (ages 6+) and those with Rett syndrome. Camp Directors, Maria and Brooke, along with trained volunteers will provide fun, safe camp activities such as arts & crafts, team building, and games in a multisensory, inclusive setting. You can register your child (ren) for the entire day or just one session: morning (9am to noon) or afternoon (1:15 to 3:30pm). There is no fee to attend the camp.

Day camp includes non-medical supervision and supplies for activities. Please pack your child(ren) a hearty snack & drink as appropriate. (No refrigeration available). Parents are welcome to assist with snack if needed.

**NOTE:** Directors and volunteers are not responsible for distribution of medications or personal care assistance. Parents are welcome to check their child out of day camp at any time to address these needs and provide support.

**Day camp registration deadline is April 14**, please indicate your childcare needs on the registration page. The camp area will be open from 8:45am to 3:30pm on Saturday. It will be closed over the lunch hour. Everyone is welcomed to eat the lunch provided for Rett Ed Day participants.

**NOTE:** There will be a private changing area with a cot for those with special needs. Please bring your own supplies.