

Rett Syndrome Education Day



Time
Saturday, April 20, 2024
8:30 am to 5pm

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

**Registration is required
for this free event**
gillette.mn/rett2024



**Registration
Deadline**
Saturday, April 6

Welcome to the 17th Rett Syndrome Education Day!

- 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 Kayla Stielow:
krstielow@gmail.com 320-406-4387

Schedule

9:00-9:15am	Welcome by Mitch Bleske and Matt Dahms
9:15-10:15am	IRSF Updates IRSF high level Research updates, and introduction to the MyRettAlly App, and a review of the Communication Guidelines.
10:15- 10:30am	Break
10:30-10:45pm	Research Update from U of M Speaker: Bryanne Byers Updates on current research from our partners at the University of Minnesota.
10:45-11:15pm	Gillette Children's Update Speakers: Dr. Tim Feyma and Dr. Arthur Beisang Dr. Feyma will update us on the current status of gene therapy, and what we should expect to see in the future, and Dr. Beisang will speak on scoliosis in individuals with Rett Syndrome.
11:15-12:00pm	Make-a-Wish Foundation Speaker: Carleen Melin Carleen from the Make-a-Wish Foundation of Minnesota will speak to us about how to access and utilize their services for our girls and women.
12:00-1:00pm	Lunch/Networking
1:00-1:45pm	Special Needs Trusts Speaker: Brad Sarkauskas, JD: Heritage Law Office Brad from Heritage Law Office will give all of our Families an introduction to the steps and processes involved in establishing special needs trust for individuals with Rett Syndrome.

1:45-2:00pm **Break 2**

2:00-3:00 pm **Break out Sessions**

Aquatherapy Speaker: Ailene Tisser (*virtual)
Co-founder Ailene of Swim Angelfish will give a presentation on the best practices and benefits of aqua-therapy for individuals with Rett Syndrome.

IEPs Speaker: Robbi Weil, PACER Center
Robbi from the PACER center will lead a guided discussion on the process of establishing an effective IEP for the child in your care, as well as explain the legal rights and responsibilities of guardians throughout the Special Education experience.

Non-Parent Caregivers Moderator: TBA
An open discussion for non-parent caregivers that are a part of the Rett Syndrome community.

3:00-3:45pm **Veteran Parents Panel: The Good, The Bad, The Ugly**
Speakers: Mary Kallstrom, Susan Murakami, Teresa Simonett, Jaette Carpenter and Moderator: MaryAnn Nelson

Bring your questions and listen to the experiences and expertise of these veteran parents who we are lucky to have in our community!

3:45-3:50pm **Thank you by Kayla Stielow**

4:00-5:00pm **Social Time**
Stick around for drinks and socialization!

Panelists/Presenters

Join your fellow midwestern Rett community members as well as our great speakers from:

International Rett Syndrome Foundation
Gillette's Center of Excellence
University of Minnesota
Make-a-Wish Foundation
Heritage Law Office
Swim Angelfish
PACER Center

Hotel/Accommodations

DoubleTree by Hilton, 411 Minnesota Street, St. Paul, MN
651-291-8800
Group dates: April 19, 2024 - April 20, 2024.
Group code: 93M. Reservations must be made by April 5, 2024
gillette.mn/hilton