

Guide to Clinic Visits

A physician who truly understands Rett syndrome can make a big difference in your loved one's life. Expert Rett providers can help direct your child's healthcare, answer questions, and provide resources for Rett syndrome. Most clinics recommend annual visits to check in with your child and get to know your family better. Use this guide to prepare for these visits whether you are looking to visit a Rett clinic for the first time or have been taking your child to Rett clinic appointments for years.



FIND A CLINIC

The International Rett Syndrome Foundation (IRSF) has designated 18 Centers of Excellence (CoE) across the United States to make it easier for families to identify an expert provider for their loved one with Rett syndrome. To find a CoE near you, see listing on back side.



ASK BEFORE YOUR VISIT

Call the clinic coordinator at the CoE you are interested in visiting to discuss your child's current status and needs.

- What kind of insurance is accepted at the clinic? Is there a financial assistance program?
- What must be done before the visit?
- Do certain diagnostic tests need to be completed? Is a genetic testing report required?
- Is there intake paperwork to complete?
- What does a typical visit look like? Is there a schedule available?
- What specialists will we see during the visit? What if a specialist we want to see isn't a part of our clinic visit?
- Can your clinic help me find specialists closer to my home and will your clinic work with them?

COMMON CLINIC SPECIALTIES

- Neurology
- Gastroenterology
- Genetics
- Physical Medicine
- AAC/Speech Therapy



FACILITATE YOUR CLINIC VISIT

- Write questions for the team ahead of time and bring them with you to the visit.
- Ask about nearby recommended restaurants, attractions, and available discounts.
- Request special accommodations if needed (e.g., larger room, wheelchair-friendly taxi service, etc.).
- Clinic visits may take several hours. Pack adequate supplies for your child (diapers, clothes, feeding supplies, etc.), items to comfort your child and for yourself as well (books, toys, food, electronics, snacks, etc.).



ASK AT THE END OF YOUR VISIT

- Will I receive a written report with recommendations?
- Is the CoE team available to answer questions and concerns moving forward? How do I contact my CoE team?
- How will the CoE team of experts work with our local care team?
- How often will we visit the CoE experts at your Rett clinic? Are telehealth visits available?

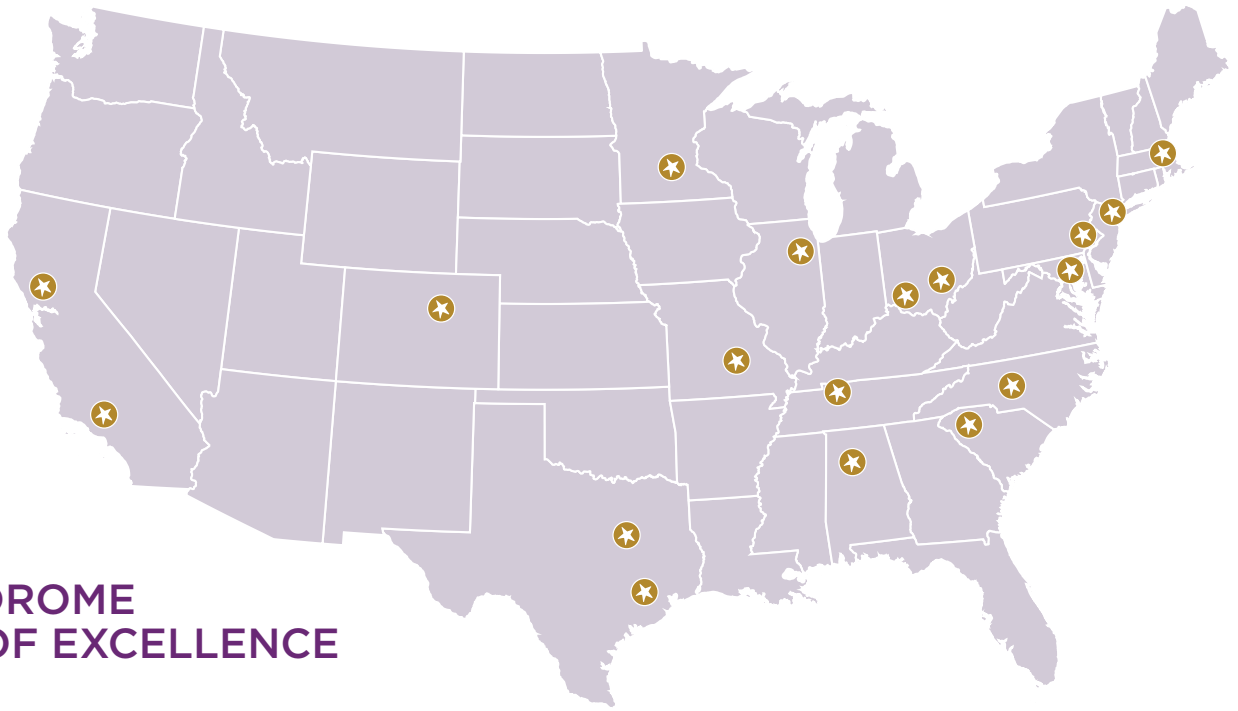


SUPPORT YOUR LOVED ONE'S HEALTHCARE

- Download the [Rett Syndrome Primary Care Guidelines](#) to share with your child's primary care doctor.
- Check out [Rett Research Ready™](#) and ask about clinical trials and other opportunities to participate in research such as the [Rett Syndrome Registry](#).
- Identify [resources that are available in your state](#) and connect with your [state's family empowerment representative](#).

RETT SYNDROME REGISTRY™ (RSR)

The RSR was designed to gather caregiver reported information as well as clinical data collected as part of a normal clinic visit at a CoE. This combination of data is essential for clinical trial design to increase the chances of clinical trial success and to help bring curative treatment options to families. Ask your CoE about participating.



RETT SYNDROME CENTERS OF EXCELLENCE

ALABAMA – BIRMINGHAM

UAB/Children's of Alabama Rett Syndrome Clinic – University of Alabama at Birmingham
205.638.6879

CALIFORNIA – LOS ANGELES

Rett Syndrome Clinic – Children's Hospital Los Angeles
323.361.2471

CALIFORNIA – OAKLAND

Katie's Clinic for Rett Syndrome – UCSF Benioff Children's Hospital Oakland
510.595.5458

COLORADO – AURORA

Rett Clinic – Children's Hospital Colorado
720.777.4363

ILLINOIS – CHICAGO

Rush Rett Care Program – Rush University Medical Center
312.942.3034

MARYLAND – BALTIMORE

Rett and Related Disorders Clinic – Kennedy Krieger Institute
443.923.2778

MASSACHUSETTS – BOSTON

Comprehensive Rett Syndrome Clinic – Boston Children's Hospital
617.355.2063

MINNESOTA – ST. PAUL

Rett and Rett Related Disorders Clinic – Gillette Children's Specialty Healthcare
651.228.6455

MISSOURI – ST. LOUIS

Rett Spectrum Clinic – St. Louis Children's Hospital
314.454.6120

NEW YORK – BRONX

Tri-State Rett Syndrome Center – Montefiore Medical Center
718.920.4378

NORTH CAROLINA – CHAPEL HILL

Rett Syndrome Clinic – The University of North Carolina at Chapel Hill
984.974.1401

OHIO – CINCINNATI

Vinaya Rett Syndrome and Related Spectrum Disorders Clinic – Cincinnati Children's Hospital Medical Center
513.636.4222

OHIO – COLUMBUS

Rett Syndrome Clinic – Nationwide Children's Hospital
614.722.4625

PENNSYLVANIA – PHILADELPHIA

Rett Syndrome Clinic – Children's Hospital of Philadelphia
267.426.1242

SOUTH CAROLINA – GREENWOOD

Greenwood Genetic Center
864.941.8100

TENNESSEE – NASHVILLE

Vanderbilt Rett Syndrome Clinic – Vanderbilt University Medical Center
615.936.5536

TEXAS – DALLAS

Rett and Related Disorders Clinic – University of Texas Southwestern/Children's Health Dallas
214.456.2768

TEXAS – HOUSTON

Blue Bird Circle Rett Center – Texas Children's Hospital
832.822.7388

For the most up to date information, visit rettsyndrome.org/clinics.

ABOUT THE INTERNATIONAL RETT SYNDROME FOUNDATION

As the leading Rett syndrome research and advocacy organization, the International Rett Syndrome Foundation (IRSF) builds upon our nearly 40-year commitment to breakthrough discoveries and life-changing advancements in research toward a cure while supporting families affected by Rett syndrome. Through our legacy foundation pioneers, we have invested over \$54M in research that has led to identifying Rett syndrome's cause, proving Rett syndrome is reversible in mice, and developing multiple clinical trials for Rett syndrome. We fight for families living with Rett syndrome and a world without it. Learn more at www.rettsyndrome.org.