

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 21 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.).
- Talk to your clinician about the possibility of treating your loved one with DAYBUE™ (trofinetide), the 1st ever FDA-approved treatment for Rett syndrome.



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 Rett clinic? Are telehealth visits available?

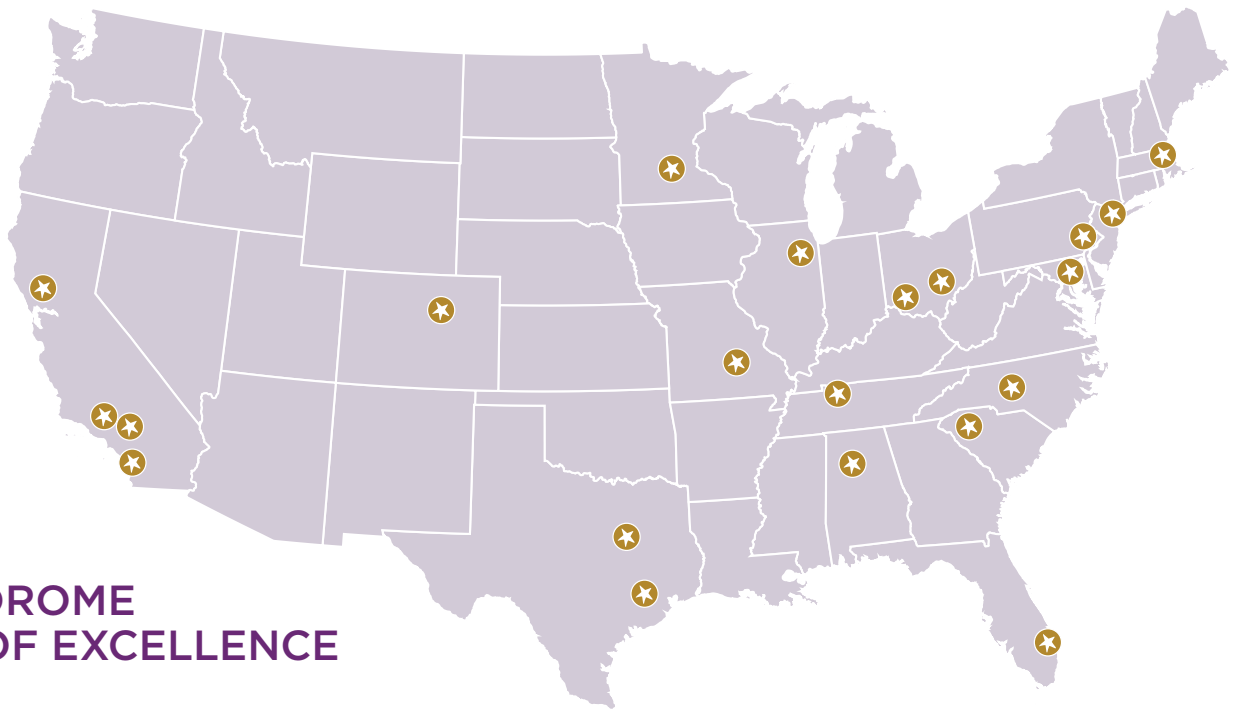


SUPPORT YOUR LOVED ONE'S HEALTHCARE

- Download the [Rett Syndrome Comprehensive Care Guidelines](#) and [Quick Reference Guide](#) 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

BIRMINGHAM, ALABAMA

*UAB/Children's of Alabama
Rett Syndrome Clinic -
University of Alabama
at Birmingham*

LOS ANGELES, CALIFORNIA

*Rett Syndrome Clinic -
Children's Hospital Los Angeles*

OAKLAND, CALIFORNIA

*Katie's Clinic for Rett Syndrome -
UCSF Benioff Children's
Hospital Oakland*

ORANGE, CALIFORNIA

*CHOC Rett Syndrome
Center of Excellence -
Children's Hospital Orange County*

SAN DIEGO, CALIFORNIA

*UCSD/Rady Children's Hospital
Rett Syndrome and Related
Disorders Clinic*

AURORA, COLORADO

*Rett Clinic -
Children's Hospital Colorado*

MIAMI, FLORIDA

*Rett Syndrome Clinic -
Nicklaus Children's Hospital*

CHICAGO, ILLINOIS

*Rush Rett Care Program -
Rush University Medical Center*

BALTIMORE, MARYLAND

*Rett and Related Disorders Clinic -
Kennedy Krieger Institute*

BOSTON, MASSACHUSETTS

*Comprehensive Rett Syndrome Clinic -
Boston Children's Hospital*

ST. PAUL, MINNESOTA

*Rett and Rett Related Disorders Clinic -
Gillette Children's Specialty Healthcare*

ST. LOUIS, MISSOURI

*Rett Spectrum Clinic -
St. Louis Children's Hospital*

BRONX, NEW YORK

*Tri-State Rett Syndrome Center -
Montefiore Medical Center*

CHAPEL HILL, NORTH CAROLINA

*Rett Syndrome Clinic -
The University of North Carolina
at Chapel Hill*

CINCINNATI, OHIO

*Vinaya Rett Syndrome and
Related Spectrum Disorders Clinic -
Cincinnati Children's Hospital
Medical Center*

COLUMBUS, OHIO

*Rett Syndrome Clinic -
Nationwide Children's Hospital*

PHILADELPHIA, PENNSYLVANIA

*Rett Syndrome Clinic -
Children's Hospital of Philadelphia*

GREENWOOD, SOUTH CAROLINA

Greenwood Genetic Center

NASHVILLE, TENNESSEE

*Vanderbilt Rett Syndrome Clinic -
Vanderbilt University Medical Center*

DALLAS, TEXAS

*Rett and Related Disorders Clinic -
University of Texas Southwestern/
Children's Health Dallas*

HOUSTON, TEXAS

*Blue Bird Circle Rett Center -
Texas Children's Hospital*

*For the most up-to-date contact information for each clinic,
scan the QR code or 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.