

# You are not alone

We know that the diagnosis of Rett syndrome can be overwhelming. You may be confused, scared, frustrated, angry or uncertain, and your emotions may change from day to day, sometimes even hour to hour. We know. We've been there ourselves.

But you are not alone. You are now part of [Rettsyndrome.org](http://Rettsyndrome.org): a network of families, researchers, clinicians, professionals, volunteers and supporters who are determined to make a difference. If your child or someone else close to you has recently been diagnosed, we encourage you to **connect with Rettsyndrome.org** right away to receive unbiased and comprehensive information. There are a lot of acronyms in this brochure. We know there is a lot of new language to learn and new systems to navigate. We will send you the *Rett Syndrome Handbook, 2nd ed.*, which is an excellent reference book covering all aspects of Rett syndrome, and we will connect you with families in your local community who can be your lifeline and may become better friends than you ever imagined having.

We have created this **First 100 Days Pathway** to simplify and prioritize this important period of time for you and your family. While you are adjusting to the diagnosis, it is also a critical window of development for your child, and we want to help all of you get on track and back in the driver's seat as quickly as possible. Keep this handy, and refer to it regularly. Most importantly, reach out for us. We are here, we understand, and we can help. Research is promising, and our entire community is ready to support you.



[www.rettsyndrome.org/for-families/new-diagnosis](http://www.rettsyndrome.org/for-families/new-diagnosis)

## 30 Days



### FAMILY AND COMMUNITY

- Tell people.
- Surround yourself with supportive, positive people.
- Connect with your own feelings.
- Contact [Rettsyndrome.org](http://Rettsyndrome.org) for support and information.
- Create a personalized Awareness Card through [Rettsyndrome.org](http://Rettsyndrome.org) to simplify educating others.
- Ask a family member or friend to accompany you to all appointments, to help with your child or take notes so you can focus and remember important information

### MEDICAL

- Organize records, tests, reports, contacts.
- Prioritize your child's challenges and focus on these right now.
- Provide Rett specific growth charts to physicians: <http://www.rettsyndrome.org/for-families/resources>

### SERVICES

- Children younger than three receive Early Intervention (EI) services through your State Department of Health.
- Set up evaluations for children ages 3 and older to determine their services in school and secured in the Individualized Education Plan (IEP).

### THERAPY

- What therapy is she currently receiving? Is this what is recommended for a child with Rett syndrome?
- Prioritize your top 3 concerns today and focus on these (i.e. Communication, Fine Motor, Gross Motor, Sleep, Eating/Drinking/Nutrition and Growth).
- Make a consultation appointment with each of your child's therapists to discuss treatment now that you have a diagnosis. Discuss positioning, mobility, equipment, feeding, communication, sensory needs.

### SCHOOL

- Make a consultation appointment with your child's Early Interventionists or Educators to discuss the learning and development plan now that you have a diagnosis.
- Turning 3 soon? Do you know about the Individualized Education Plan (IEP) process?

### RESEARCH

- Research which clinicians, specialists and therapists your child needs to see. Talk to other parents for recommendations.
- Educate yourself on current studies.

### RECORD

- Start a video record of any unusual behavior to show your physician.
- Track progress or regression.
- Write any changes in your log book.

### AWARENESS

- Set up a fundraising page through [Rettsyndrome.org](http://Rettsyndrome.org) in your child's honor. People want to help if you tell them how.

## 60 Days

### FAMILY AND COMMUNITY

- Talk to your spouse, other children, and family members to connect with their feelings.
- Tell family and friends exactly how they can help. They want to, but don't always know how to ask.
- Connect with other families who are on the same journey as you. [Rettsyndrome.org](http://Rettsyndrome.org) can connect you with families directly or online.

### MEDICAL

- Schedule appointments with specialists for baseline evaluations and assessments (neurologic exam, orthopedics, swallow study, EEG, EKG, etc).
- Record any changes in your child. Update your binder.
- Organize new paperwork in your binder. Purge and add as needed.
- Review your calendar for upcoming appointments.

### THERAPY

- Schedule a team meeting to review and discuss beneficial therapies specific to Rett syndrome now that everyone has learned more about Rett syndrome.
- Schedule a team meeting to discuss goals and open lines of communication.

### SCHOOL

- Keep an open line of communication.
- Provide educators with research of how children with Rett syndrome learn best.

### INSURANCE

- Review your insurance for which, if any, therapies are covered to make sure you are getting the most from your providers.
- Document everything.

### LEGAL RIGHTS

- Your child might be entitled to services you were not aware of or had not considered

### RESEARCH

- Waiver Programs and Federal and State sources of support.
- Special Needs Wills and Trusts.

### AWARENESS

- Plan or attend a fundraiser or Rett syndrome event in your area.





## FAMILY AND COMMUNITY

- Research different activities for special needs in your area.
- Research a special recreational association in your area with trained staff that provides programs and special events.
- Ask family and friends for help with appointments or therapies. They want to help.
- Find a caregiver or sitter for respite.

## MEDICAL

- Schedule any remaining tests and appointments, or follow-up appointments.

## THERAPY

- Check the progress of your child.
- Communicate any best practices you have learned.

## SCHOOL

- Check on your child's progress.
- Communicate any best practices you have learned.

## RESEARCH

- Research additional therapy options or specialists, such as therapeutic riding, aquatherapy and more.
- Stay up to date with current research and studies.
- Locate and register for a Rett syndrome conference or webinar.

## AWARENESS

- Continue to spread awareness by sharing your child's story.
- Ask your family to help you plan or attend a fundraiser or Rett syndrome event.

## Next Steps

- Stay in contact with Rettsyndrome.org
- Support comes in many forms, and your needs will change over time.
- We will meet you where you are and help you take the next steps



## Additional Resources

### MAKE AN "ALL ABOUT ME" BOOK

Help others understand Rett syndrome, your child, how Rett syndrome affects your child specifically and how to work with her/him. Include schedules, emergency contacts, likes and dislikes, sleep patterns, feeding information, personal care information and any other information related to your child's everyday care, comfort, and happiness. Include pictures of your child, your family, enjoying favorite activities, and more.

### ORGANIZE A BINDER FOR YOU

Three ring binder with tabs including:

- **REPORTS:** Include copies of all diagnostic reports, such as your Rett syndrome genetic diagnosis or EEGs. Ask for an electronic copy of results.
- **PRESCRIPTIONS:** Include a copy of all prescriptions for any medications, specialist equipment and therapies.
- **SPECIALISTS:** Include contact information for all specialists. Specialists may include: Physician/Pediatrician, Neurologist, Cardiologist, Gastroenterologist (GI), Pulmonologist, Orthopedist, ENT, Allergist, Ophthalmologist, Dentist, Orthotist, PT, OT, Communication Specialist, and Nutritionist.
- **THERAPIES:** Include contact information for all therapists (PT, OT, AAC, etc). Include their reports and any handouts for exercises.
- **EQUIPMENT:** Include receipts from equipment vendors, notes on how to use equipment and contact information. Know whom to call if equipment breaks.
- **PROGRAMS:** Include information about the programs or organizations in which your child participates.
- **EARLY INTERVENTION (EI):** Include documents and therapy reports for children under three years old receiving services from the state.
- **INDIVIDUALIZED FAMILY SUPPORT PLAN (IFSP):** Include your child's IFSP and any related documents for authorized support services such as Respite, or personal care supplies.
- **INDIVIDUALIZED EDUCATION PLAN (IEP):** Include your children's IEP and any documents related to school for children three and older.

### OTHER

Contact gas and electric company, and emergency departments (fire, police, etc) to let them know you have a child who requires special needs in case of power outage or other emergency, and inquire about possible Medical Baseline Allowance programs.

**Contact** your local DMV to apply for a Handicap Parking Pass, your child is eligible.



OUR MISSION is to fund research for treatments and a cure for Rett syndrome while enhancing the overall quality of life for those living with Rett syndrome by providing information, programs, and services. Rettsyndrome.org funds high-quality, peer reviewed research grants and programs. The organization hosts the largest gathering of Rett syndrome researchers and clinicians to establish research direction for the future. Rettsyndrome.org, a 501(c)3 organization, earns Charity Navigator's most prestigious 4-star rating year after year.

THE CORE MISSION of Rettsyndrome.org is to accelerate full spectrum research and empower families with knowledge and connectivity.

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800.818.RETT (7388) • [www.rettysyndrome.org](http://www.rettysyndrome.org)  
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FIRST  
100 DAYS  
PATHWAY  
with Rett syndrome