

# Rett Syndrome Global Registry

In the first quarter of 2021, the **Rett Syndrome Research Trust** will be launching the **Rett Syndrome Global Registry**, a parent/caregiver-driven registry that will tap into your valuable day-to-day experience with Rett, provide you with new and unique tools to manage your child's needs, while advancing research and therapeutic development.

## Why do we need a patient registry?

- Parents have at their disposal **invaluable and comprehensive information** about their child which, to date, has been limited to what is reported at a doctor's visit. By contributing this information regularly from home, parents can be partners in the research effort by sharing information about their child with fellow parents, clinicians, biopharma and scientists.
- **Any parent of a child with Rett, from anywhere in the world, can contribute to the registry** from the comfort of their home. Living near a Rett clinic or having the financial resources to travel to one are no longer limiting criteria to contribute to Rett research.
- Parents can **augment the Rett knowledge base and accelerate therapeutic development** by providing insights into their experience and the impacts of living with Rett.
- The **Rett Syndrome Global Registry** has the potential to **revolutionize our children's clinical management**, centralizing key information about your child accessible anywhere internet is available, while advancing research towards a cure.

## How do we envision the registry being used?

We anticipate that the registry will bring tangible benefits to parents, physicians, scientists and biopharma in a win-win situation for all. **Here's how.**

- In addition to basic information about your child's experience, the registry will allow parents/caregivers to **track and graph specific symptoms, skills, medications, therapies**, or other items– you decide what and how often to track. The tracker will allow parents to enter medications, therapies, diet, menstrual cycles, illnesses, hospitalizations and more allowing for visualizing change, detection of trends and potential correlations, as well as helping parents and clinicians see the impact of care over time.
- **A mobile app will be available to allow you to see your data and contribute** to items you would like to track from any smart phone or other hand-held device in the moment or when you choose to set reminders or receive notifications.
- **The registry will allow parents to contribute** to addressing research questions in the following ways:
  - Participate in remote clinical trials**
  - Test, develop, or validate clinical trial outcome measures** such as biosensors that can collect direct measurements in your child like heart rate, breathing, or oxygen levels
  - Test, develop and validate questionnaires or rating scales** that can be or are used in clinical trials
- The registry will allow clinicians and scientists to **access a high-quality dataset** to answer existing research questions and ask new ones.
- The information in the registry will also **help companies with clinical trial design**, ensuring they understand if the study they would like to run is feasible and can be enrolled. And it will also **help with recruitment** in that studies that you may qualify for can be communicated to you if you choose.

**Additional information** about the registry will be shared as we approach the launch date. Become a **Registry Pioneer** to get early access to the registry and to input your child's data.