

# THE NATURAL HISTORY STUDY

## FOR RETT SYNDROME, MECP2 DUPLICATION, AND RETT-RELATED DISORDERS



Rett Consortium

Rett Syndrome,  
MECP2 Duplication,  
& Rett-Related Disorders



### WHAT IS IT?

Natural History Studies track the natural course of a disease over time. Knowledge of a disease's "natural history" is essential, particularly for rare diseases, which by their very nature are poorly understood. **The Natural History Study for Rett Syndrome, MECP2 Duplication, and Rett-related Disorders** is a 5 year, observational study that seeks to gather as much data as possible about children and adults with Rett syndrome and related disorders. This includes collecting information about development, growth, nutrition, and quality of life over time.



### WHY IS IT IMPORTANT?

The information you provide as a participant will be used to

- Improve the understanding of Rett syndrome
- Raise clinical care standards
- Stimulate more clinical research & better prepare the community for future clinical trials.
- Aid in development of biomarkers and outcome measures



### WHO CAN PARTICIPATE?

This critical study continues to seek girls and boys of all ages with Rett syndrome (classical or atypical), *MECP2* Duplication, or related disorders that involve mutations in *CDKL5*, *FOXG1*, and other *MECP2* mutations that don't fulfill the consensus criteria for Rett syndrome.



### HOW DO I PARTICIPATE?

In order to participate, you must personally contact the institution by phone or by email. Full location details available at [www.rettsyndrome.org](http://www.rettsyndrome.org).

### CONTACT INFORMATION

#### UNIVERSITY OF ALABAMA AT BIRMINGHAM

1.800.822.2472, ext. 7

#### UNIVERSITY OF CALIFORNIA, SAN DIEGO

1.858.246.2288

#### UCSF BENIOFF CHILDREN'S HOSPITAL OAKLAND

1.925.979.4055

#### UNIVERSITY OF COLORADO

1.720.777.5514

#### RUSH UNIVERSITY MEDICAL CENTER

1.312.942.0079

#### BOSTON CHILDREN'S HOSPITAL

1.617.355.5230

#### GILLETTE CHILDREN'S SPECIALTY HEALTHCARE

1.651.325.2331

#### WASHINGTON UNIVERSITY SCHOOL OF MEDICINE & ST. LOUIS CHILDREN'S HOSPITAL

1.314.454.4267

#### UNIVERSITY OF ROCHESTER

1.585.275.2808

#### CINCINNATI CHILDREN'S HOSPITAL MEDICAL CENTER

1.513.803.7935

#### CHILDREN'S HOSPITAL OF PHILADELPHIA

1.267.426.5171

#### GREENWOOD GENETIC CENTER

1.864.941.8100

#### VANDERBILT UNIVERSITY

1.615.343.4586

#### BAYLOR COLLEGE OF MEDICINE

1.832.822.7388



“Knowledge of natural history is essential for developing more efficient clinical trial designs. It also could help reduce the length and cost of drug development and, possibly, contribute toward greater predictability of clinical development programs.”

~Janet Woodcock, M.D.,  
Director of FDA's Center for  
Drug Evaluation and Research

