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## RETT SYNDROME NATURAL HISTORY STUDY

The purpose of this natural history study is to establish a phenotype-genotype correlation over a broad spectrum of Rett syndrome phenotypes including the longitudinal pattern of progression of clinical features, quality of life, and longevity across this cohort.

**Location:** Various (See list below). A child is enrolled and seen at one specific study site. Assessments are scheduled privately in Alabama, Massachusetts, South Carolina, and Texas. Individual assessments are scheduled into specialized clinic weekends sponsored by IRSF (see below for dates) in California, Florida, Illinois, and New Jersey.

**Target Enrollment:** 1,000 individuals fulfilling consensus clinical criteria for Classic or Variant Rett Syndrome or individuals with MECP2 mutations who do not meet the clinical criteria. All ages will be eligible. Patients must be able to travel to study sites for annual evaluations (for those 6 years or older) or bi-annual evaluation (for those through age 5).

### The data collection sites include:

- Birmingham, AL
- Oakland, CA – *travel site*
- Tampa/Miami (alternating), FL - *travel site*
- Chicago, IL - *travel site*
- Boston, MA
- New Brunswick, NJ – *travel site*
- Greenwood, SC
- Houston, TX

TRAVEL SITE	2013 SPRING DATES	2013 AUTUMN DATES
<b>Florida</b>	Jan 12-13, 2013 (Tampa)	June 8-9, 2013 (Miami)
<b>New Brunswick, NJ</b>	February 9-10, 2013	August 10-11, 2013
<b>Oakland, CA</b>	March 9-10, 2013	October 5-6, 2013
<b>Chicago, IL</b>	April 13-14, 2013	November 2-3, 2013

**How to Participate:** In order to participate in a study, you must personally contact the study coordinator of any of the participating institutions by phone or by e-mail. Please use the information below to inquire about participation. If you wish to enroll at one of the *travel* sites (CA, FL, IL, or NJ) please contact Jane Lane, lead research coordinator, at the University of Alabama for participation information.

### Site Coordinators Contact Information:

[The Blue Bird Circle Rett Center,](#)  
Texas Children's Hospital/Baylor  
College of Medicine  
Coordinator: Judy Barrish, RN, BSN  
[jobarris@texaschildrenshospital.org](mailto:jobarris@texaschildrenshospital.org)  
Ph: 832-822-7388 or 888-430-7388

[University of Alabama at  
Birmingham,](#)  
Birmingham, AL  
Coordinator: Jane Lane, RN,  
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Ph: 205-934-1130

[Greenwood Genetic Center,](#)  
Greenwood, SC  
Coordinator: Fran Annese,  
LMSW  
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[Boston Children's Hospital  
Rett Center](#)  
Boston, MA  
Coordinator: Kate Barnes, BSc  
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