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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)

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

SITE	SPRING DATES	AUTUMN DATES
Florida X - Tampa	Jan 14 – 15, 2012	
Florida XI - Miami		June 9 - 10, 2012
Jew Jersey X	February 11 – 12, 2012	
New Jersey XI		August 18 – 19, 2012
Oakland XII	March 17-18, 2012	
Oakland XIII		October 6-7, 2012
Chicago VII	April 14 - 15, 2012	
Chicago VIII		October 27-28, 2012

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.

Site Coordinators Contact Information:

[The Bluebird Circle Rett Center](#)
Texas Children's Hospital/Baylor
College of Medicine
Coordinator: Judy Barrish, RN, BSN
jobarris@texaschildrenshospital.org
Phone: 832-822-1781

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

[Greenwood Genetic Center](#)
Greenwood, SC
Coordinator: Fran Annese, LMSW
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Phone: 864-941-8100

[Rett Center](#)
Boston Children's Hospital
Coordinator: Kate Barnes
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