1966
Dr. Andreas Rett publishes paper suspecting a new, unique syndrome

1983
Rett syndrome gains international recognition

1983
International Rett Syndrome Association launches

1984
Diagnostic criteria is published

1988
Established: Rett syndrome is not degenerative

1999
Causative gene associated with Rett syndrome

1999
Rett Syndrome Research Foundation formed

2000
4 U.S. Rett syndrome clinics see patients, conduct research

2004
NIH Natural History Study (NHS) begins

2006
7 U.S. Rett syndrome clinics see patients, conduct research

2007
Rett syndrome reversed in a mouse model

2007
IRSF doing business as Rettsyndrome.org founded through the merger of IRSA and RSRF

2010
First clinical trial in RTT supported by Rettsyndrome.org: IGF-1

2010
Patient-derived stem cell model for Rett syndrome – a promising cellular tool for drug screening in a petri dish

2013
Phase 2b clinical trial of IGF-1 begins

2013
First multi-site clinical trial in RTT begins: NNZ-2566 (now Trofinetide) in adults and older adolescents

2014
Drug screening Scout program begins

2014
NIH NHS of Rett and Related Disorders begins

2014
Multi-site pediatric clinical trial of Trofinetide begins

2016
14 clinics designated as Rett Syndrome Clinical Research Centers of Excellence. A total of 19 U.S. Rett syndrome clinics see patients, conduct research.

2016
First multi-site, multi-country clinical trial slated to begin: Sarizotan

Rettsyndrome.org
ACCELERATING RESEARCH. EMPOWERING FAMILIES.