IMPACT REPORT
2016

OUR MISSION

Accelerate full spectrum research for treatments and a cure for Rett syndrome

Empower families with information, education and connectivity

LOOKING AHEAD

2017

Launch of new Phase 2 clinical trial with Anavex 2-73

Data analysis of the completed Phase 2 clinical trials with Trofinetide and IGF-1

Enrollments to the NHS at 14 Rett syndrome Clinical Research Centers of Excellence throughout the U.S.

DONATE
www.rettsyndrome.org/donate

PARTICIPATE
www.rettsyndrome.org/get-involved

SIGN UP
www.rettsyndrome.org/join

Rettsyndrome.org is a 501c(3) non-profit corporation registered as the International Rett Syndrome Foundation and established in 2007 through the strategic merger of the Rett Syndrome Research Foundation and the International Rett Syndrome Association.

©2017 Rettsyndrome.org
We invested $2.1 million to support new research grants, to continue current research programs.

Rettsyndrome.org designated 14 clinics as Research Centers of Excellence.

To date, we have awarded over $40 million cumulative research dollars in a quest to accelerate treatments and find a cure.

Rettsyndrome.org, along with board members and families, undertook an ambitious advocacy campaign to enable Rett syndrome research to be funded by the Department of Defense. The campaign was a success and Rett syndrome is one of only 40 areas of study eligible for up to $278 million of DoD research funds in 2016.

Phase 2 trial in children ages (5-15) started enrollment in March 2016 and closed enrollment in November 2016. A total of 82 subjects were enrolled to the study. Concurrently, Neuren Pharmaceuticals is working with the FDA to design a Phase 3 pivotal study with trofinetide as a treatment for Rett syndrome.

Completed enrollment and trial study visits of 30 subjects. Final data analysis is ongoing.